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# **Genetic Democracy**

## **Philosophical Perspectives**

*Edited by*

**VEIKKO LAUNIS**

*Turku, Finland*

and

**JUHA RÄIKKÄ**

*Turku, Finland*

 **Springer**

*Editors*

Veikko Launis  
Turku  
Finland

Juha Rääkkä  
Turku  
Finland

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# Contributors

**Marko Ahteensuu** is a PhD Candidate in the Department of Philosophy at the University of Turku, Finland. He has worked in research projects on bioethics both in Finland and abroad.

mataah@utu.fi

**Vilhjalmur Árnason** is Professor of Philosophy in the Department of Philosophy and Centre for Ethics at the University of Iceland.

vilhjarn@hi.is

**Wen-Tsong Chiou** is Assistant Research Fellow in the Institutum Iurisprudentiae, Academia Sinica, Taiwan.

wentsong@gate.sinica.edu.tw

**Henk ten Have** is Director of the Division of Ethics of Science and Technology in Unesco, France.

H.Tenhave@unesco.org

**Stefán Hjörleifsson** is M.D. and Research Fellow in the Department of Public Health and Primary Health Care at the University of Bergen, Norway.

stefan.Hjorleifsson@isf.uib.no

**Niklas Juth** is Doctor of Philosophy and Senior Lecturer in Medical Ethics at Karolinska Institutet, Sweden.

niklas.juth@ki.se

**Eerik Lagerspetz** is Professor of Practical Philosophy at the University of Turku, Finland.

eerlag@utu.fi

**Veikko Launis** is Professor of Medical Ethics at the University of Turku, Finland.

vlaunis@utu.fi

**Keekok Lee** presently holds an Honorary Research Fellowship in the School of Social Sciences, University of Manchester. Previously, she held an Honorary Chair in Environmental Philosophy at the University of Lancaster.  
keekok.lee@manchester.ac.uk

**Thomas Pogge** is Professor of Political Science at the Columbia University, New York.  
tp6@columbia.edu

**Juha Räikkä** is Lecturer in Practical Philosophy at the University of Turku, Finland.  
jraikka@utu.fi

**Dr. Helena Siipi** is Assistant of Philosophy at the University of Turku, Finland.  
helsii@utu.fi

**Terence Hua Tai** is Professor and Chair in the Department of Philosophy at the National Chengchi University, Taiwan, and serves as Director of the Chengchi University Center for Science, Technology and Human Values.  
ttai@gate.sinica.edu.tw

# Introduction: The Scope and Importance of Genetic Democracy

**Veikko Launis**

This book is about the relation of new genetic knowledge and technology to ethical decision-making and democracy. The title of the volume, *Genetic Democracy*, was composed to bring into focus the at the same time complex and powerful role genetic science and technology have in contemporary democratic and value-pluralistic societies where human beings possess an ever-increasing understanding of the most basic functions of human and non-human life. The essays were written specially for this volume and appear here for the first time. The authors are all philosophers.

In a very wide sense of the term, this book is about bioethics. Since bioethics has come to be known and valued as an interdisciplinary field – with contributions not only from philosophy but also from theology, literature, history, psychology, sociology, anthropology, biology, law, and the diverse health professions – and since the ethical and social issues underlying genetics and democracy clearly have interdisciplinary dimensions, the dominantly philosophical perspective chosen in this volume may need a word of explanation. In this introductory essay, I will first try to say something about the role of philosophical reflection within the field of genetic democracy. Second, I will try to identify the major philosophical topics and questions in this book and to provide a structure for the discussion. In doing so, I will also have something to say about the notion of genetic democracy.

The last twenty years or so have witnessed a dramatic rise of interest among different experts, interest groups, legislators, policy-makers and lay people in ethical, social and environmental questions about genetic science and technology calling for decisions that often have wide and far-reaching consequences. As a result of this development, it has become almost natural to approach genetical issues (or what is sometimes now called ‘genetic technoscience’) from a multidimensional and interdisciplinary perspective. The controversial debate over genethics has unquestionably benefited from its multidimensionality and interdisciplinarity. First of all, such a discussion has been able to focus on questions that might not be readily

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V. Launis  
Professor of Medical Ethics at the University of Turku, Finland  
e-mail: vlaunis@utu.fi

addressable in the traditional (individualistic) bioethical discourse that – as many critics have pointed out – tends to accept science and the society (and often also our human nature) as presented and then to address the resulting questions of bioethics as if they were completely independent of these two (or three). Second, since our ethical thinking itself has developed and continues to develop in response to specific conditions and challenges of social and biological life, it seems clear that the new possibilities and expectations genetic science and technology create require critical and many-sided examination of current ethical thinking and theory, not just mechanical application of it. In short, then, it seems that the ethical and social issues of both human and non-human genetic research are analysed more usefully when they are tied to, and the analysis critically reflects, the present and prospective realities of genetics and its technological capabilities.

The purpose of this book is not to question the value or usefulness of the multidimensional and interdisciplinary approach to genethics but rather to complement it by drawing insight into what the authors regard to be the most important topics and issues related to genetics and democracy from a distinctively philosophical and also more global perspective. One of our main emphases in this book is that the topics and issues selected here have not only an (individualistic) ethical but also an important social and political philosophical dimension.

It is obvious that the extent to which a particular issue related to genetic democracy can usefully be discussed within such a philosophical framework depends, among other things, on the kind of issue it is. For the purposes of this volume, four kinds of philosophically and ethically relevant issues may be distinguished. These are called demand-for-reason issues, empirical ethical issues, conflicts between ethical principles, and interpretative ethical issues (or relevance issues).<sup>1</sup>

## **Demand-for-Reason Issues**

First of all, there are issues that may be characterised as *demand-for-reason problems*. There is a demand-for-reason problem when we consider a certain practice or procedure to be morally permissible (for instance, using genetically modified animals rather than human beings as cancer models in lethal research in medical science) or impermissible (for instance, replicating the genetic constitution of human beings by reproductive cloning) but are unable to specify on what morally or philosophically relevant grounds it may be considered so, even though there is a morally – and sometimes also legally – justifiable demand for providing such a ground.

The chapters by Helena Siipi and Eerik Lagerspetz address demand-for-reason problems directly, although (following the spirit of this volume) both writers bring a wider, Western political philosophical perspective to the issues they are dealing with. In ‘The Prerequisites of Genetic Democracy’, which is also the opening chapter of this volume, Siipi discusses four general ideals or requirements for democracy with respect to new genetic research and gene-technology: effective participation and public engagement, equality and non-discrimination of interests and values,

personal autonomy and freedom of choice, and transparency. These prerequisites, she points out, are usually taken for granted when discussing ethical, social and environmental issues raised by modern bioscience and technology. The interesting thing to observe is that, in current ethical and political thinking, these requirements are considered to be exceptionally stringent and binding in the context of *genetic* research and *gene*-technology. The demand-for-reason question is therefore this: Is there *really* something special about genetic research and gene-technology, or are we just, as Søren Holm puts it, misled 'by the fact that genetics is the latest in a long range of scientific fields which have at different times captured public attention?'<sup>2</sup> As soon as we begin to wonder whether it is true that genetic data and genetically modified organisms (GMOs) have a morally special or exceptional status, some explanation and justification for the prevailing exceptionalist view is needed. Although Siipi goes a good way to answer this question, it is no surprise that it takes the whole of this book (and probably even more) to provide a full analysis of it.

Lagerspetz's main focus is on the possibility and meaningfulness of (bio)ethical expertise in democratic societies. The idea of an ethical expert (a person or body who knows morally better and is therefore to take, or at least share, the moral responsibility of a decision) may strike us as paradoxical, because we are used to believe that moral responsibility – unlike legal responsibility – is always on one's own shoulders and people must decide for themselves what is morally right and wrong and what they in general ought to do. Yet the commonsense opinion seems to be that there can be experts in morality as there are in science, law and the various other fields.

Seeing the issue from a broader, political philosophical perspective, Lagerspetz maintains that although the idea of publicly recognised ethical expertise is commonly accepted and highly appreciated both by political decision-makers and the members and nominators of ethics councils and similar bodies, it is generally incompatible with democratic theory. To be sure, the democratic process may leave some room for expertise. However, as Lagerspetz points out, the authority of ethical experts differs in an important way from that of other decision-makers, such as politicians, judges and scientific experts. The difference is that the latter kind of experts may, at least sometimes, appeal to their background legitimations when justifying difficult decisions.

## **Empirical Ethics Issues**

Secondly, some issues are, or turn out to be, ethically controversial largely because relevant empirical and scientific facts are in dispute. These may be called *empirical ethical problems*. A possible example of this category of issues is the question whether the development and cultivation of genetically modified crops and/or food products should be rejected because of the risk they are believed to pose to the environment and people's health. Opinion formation in these issues requires knowledge about the predictable advantageous and disadvantageous (medical, social, psychological, political and economic) consequences of the activities and policy

options considered. In theory, such an assessment should not be too difficult to carry out. In practice, however, the situation is different. This is because the consequences of novel technologies and scientific innovations are usually difficult to predict, and the actual and overall consequences of using genetic science and technology for some specific purposes depend, among other things, on the social and political setting in which the application takes place.

At first glance, it may seem that the contribution of philosophers to discussions of these issues must be quite limited. However, as Marko Ahteensuu (in ‘The Precautionary Principle and the Risks of Modern Agri-Biotechnology’) and Niklas Juth (in ‘Values, Rights and GMO: Against Radicalism’) show, this is not the case. While it is true that much of the current debate about the acceptability of modern agri-biotechnology has focused on empirical risks and safety issues, it does not follow that there are no relevant philosophical questions to be addressed. One such question concerns the status and interpretation of the influential and hotly debated ‘precautionary principle’ that is called into play in societal risk governance by two aspects about the current state of scientific knowledge on the risks of modern agri-biotechnology: the fact that there are uncertainties concerning the long-term environmental threats and health hazards and the fact that many alleged risks are matters of ongoing scientific disputes. In his chapter, Ahteensuu not only provides useful conceptual and ethical tools for non-specialists to form reasoned beliefs and attitudes towards an adequate risk-governance of modern agri-biotechnology, but suggests a shift in the focus of the academic debate over the precautionary principle particularly by questioning a much used distinction between the strong and weak interpretation of the precautionary principle.

Another important question, addressed by Juth in his chapter, stems from the observation that the way people see and evaluate the risks and consequences of modern gene and biotechnology, and especially of modern *green* gene and biotechnology, is dependent not only on the already mentioned different social and political settings in which the application may take place but, equally interestingly, on the political philosophical position they adhere to. Using the commercial production and marketing of GMO as an example, Juth defends what he calls a ‘middle ground’ position between two radical positions, the right-based libertarian position that the commercial marketing of GMO should always be permitted and the value-based prohibitionist position that the commercial marketing of GMO should never be permitted. His conclusion is that the question of whether or not the commercial production and marketing of GMO should be allowed should be determined on a case-by-case basis, taking into consideration the specific benefits and risks of the GMOs in question.

## Conflicts Between Ethical Principles

Thirdly, there are issues that may be characterised as *conflicts between ethical principles*. A classic example would be the question as to whether a person’s assumed moral right to genetic privacy overrides his or her blood relatives’ assumed

moral right to know about their exceptional genetic status in the case of increased risk to a serious hereditary disease, such as Huntington's disease or cystic fibrosis. Issues of this kind are genuine ethical problems in the sense that the moral conflict may remain even when the empirical (scientific) and legal facts are clear and accepted by all parties involved in the disagreement.

There can be no doubt that philosophical clarification of the key ethical concepts and principles is important when issues like this are discussed. In his article 'Autonomy and Genetic Privacy', Juha Räikkä shows that the moral right to privacy and the moral right to personal autonomy or self-determination are interrelated in various important ways. He points out that many of the recent debates about (the moral limits of) genetic privacy result in conceptual unclarity, if not confusion. He argues, quite convincingly, that we would be better off if we redefined the morally and conceptually obscure notion of genetic privacy so that it would be in line with the more general right to privacy and be kept apart from the notion of self-determination with which it is so often confused.

Another important conflict problem is addressed by Terence Hua Tai and Wen-Tsong Chiou in 'Equality and Community in Public Deliberation: Genetic Democracy in Taiwan'. Tai and Chiou address some difficult issues that a fledgling democracy such as Taiwan must deal with if it is to establish a large human genetic database – the so-called Taiwan Biobank – in ways that are morally justifiable to the public. They argue, in particular, that since the indigenous people in Taiwan should be considered especially vulnerable in view of the political and social inequalities they have suffered and a long history in which they have often fallen prey to researchers surreptitiously collecting their biological samples under the guise of free health check, their perspective should be adequately represented and weighted in public deliberative forums designed to reach consensual recommendations about the feasibility of Taiwan Biobank.

By calling attention to the indigenous people's special vulnerability and unjustified inequality in Taiwan, Tai and Chiou bring out the following philosophical question: Even if indigenous requirements are given a due concern, it may not be easy to determine what increased 'equality in public deliberation' exactly means in this context. It seems clear, on the one hand, that biobank-based research should be responsive to the health needs and priorities of the community in which it is to be carried out, as well as to the fact that some of the members may be relatively incapable of informed consent due to illiteracy or unfamiliarity with the concepts of modern medicine and bioethics held by the investigators and the majority of the citizens. On the other hand, it seems equally clear that the officials and investigators should respect the professional ethical standards of their own as well as the cultural expectations of the larger society in which the research is undertaken.

## **Interpretative Ethical Issues**

Finally, there are issues that are most properly called *relevance* or *interpretation problems*. These are characteristically raised by novel technologies and new scientific in(ter)ventions. We may speak of a relevance problem when we are confronted

with a new situation in which our traditional ethical principles and concepts do not apply very well and we are unable to see which features of the situation are relevant to its moral appraisal. As Thomas Pogge puts it ('Moral Constraints on Permissible Genetic Design'), in such a situation 'we may lack not merely the sound judgment needed to apply our morality to new circumstances nor even moral intuitions that extend to the question we face, but we may even lack the very concepts in terms of which the issues before us can be thought through from a moral point of view'. To give an example of the day, whether biobank-based medical research should be understood as 'medical research involving human subjects' or merely as 'medical research on previously collected biological material and data' that can be conducted without a new informed consent or with a previously acquired 'open' or 'blind' consent is largely a relevance problem because we do not know what is morally speaking involved in the development and use of such human sample and data registries. The biobank example becomes even more telling when we are told (by the medical scientists) that in very many cases it is simply not possible to describe in detail the research that will be performed on the data at the time of collection and consent attainment.

The chapters by Vilhjálmur Árnason and Stefán Hjörleifsson, Thomas Pogge and Keekok Lee deal predominantly with this kind of issues. In 'Population Databanks and Democracy', Árnason and Hjörleifsson discuss democracy in light of the Icelandic experience of the databank recourse of DeCODE genetics biopharmaceutical company. They point out that, as far as population database research is concerned, there are different types of consent implying different visions of the citizen and also different visions of the functions of democracy. In their well-founded conclusion, only a 'dynamic ongoing consent' would adequately respect the citizens as active and reflective human beings, and would thus be in line with the prerequisites of genetic democracy (dissected by Helena Siipi in 'The Prerequisites for Genetic Democracy' of this volume).

In 'Moral Constraints on Permissible Genetic Design', Pogge outlines an ethical framework for the future prospects of human genetics. More precisely, he addresses the question about the moral status of a dramatic future form of positive genetic intervention – human genetic design. He imagines a scientifically advanced future world in which the creation of 'designer babies' would be safe, predictable and reasonably affordable. In such a model world, Pogge suggests, a morally responsible genetic policy and legislation might not only allow parents to choose top genetic endowments for their offsprings but even require them to do so at least in cases where conventional reproduction is likely to result in dramatically disadvantageous inferior endowments.

A different aspect of the same interpretative issue concerning human genetic interventions that appear to go beyond the traditional goals of medicine is discussed by Lee in 'Genetic Resources, Genetic Democracy and Genetic Equity'. She points out that while contemporary liberal democratic and welfare capitalist societies are anxious to distance themselves from the morally, socially and politically unacceptable implications of the dehumanizing eugenics of the last century, the rapidly expanding Human Genome Project may impose another serious threat at least to those who are

concerned with the value of equality. According to Lee, new developments in human genetic research that are usually considered to increase equality of opportunity could paradoxically decrease genetic democracy and lead the modern biotech-based society from being essentially a class-based meritocracy to being a caste-based feudal one.

## Interplay of the Categories

The four categories are, of course, interconnected and may occur either simultaneously or in succession. Therefore, it should be no surprise that the arguments presented by the authors in the following chapters sometimes include elements of more than just one category. This is the case for example in Lagerspetz's critical analysis of the notion of ethical expertise. To understand what the role of ethical experts should be in a democratic society, we should (as Lagerspetz himself points out) first learn what they are actually doing. Thus, besides posing the already mentioned demand-for-reason problem, the idea of ethical expertise poses an important empirical ethical problem. In the same way, besides posing an interpretative ethical problem, experiments in human enhancement techniques (as analysed by Pogge and Lee) may be said to pose a demand-for-reason problem, as these experiments are often prohibited by common consent and law without there being any well-articulated ethical ground for such a prohibition. As soon as such a ground can be articulated, objections to them will be raised and human enhancement techniques are likely to constitute new empirical ethical problems (concerning possible short and long term health risks and appropriate precautionary measures) as well as new conflicts between ethical principles.

In 'Towards Global Bioethics: The New UNESCO Declaration on Bioethics and Human Rights', Henk ten Have explains the background of the Universal Declaration on Bioethics and Human Rights and describes how it was developed and what kind of critical responses it confronted. The long and difficult process of establishing international normative standards for biomedicine and biotechnology, explained in a detailed way by ten Have, is in itself a prominent example of the interplay of, and the dynamics between, the four categories of ethical issues. While the chief aim of the Declaration was not to provide guidance in everyday bioethical decision-making and opinion formation, but to provide 'a universal framework of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics', there is no question that the use of the Declaration even for such general purposes is likely to create difficult conflicts between bioethical principles as well as difficult interpretative and demand-for-reason issues. For example, it is not clear what the sharing of benefits principle, explained in Article 15, means in the context of biobank legislation.

However, as ten Have himself points out, the new Declaration is the beginning rather than the end of a process of internationalisation and harmonisation of bioethics and improvement of genetic democracy on different levels. And of course,

the same holds true at least as much with the ten articles of this book. Taken individually, each paper tells one aspect of the story of genetic democracy from its author's own philosophical point of view.

## Notes

<sup>1</sup> Juha Räikkä and Veikko Launis, 'Geenietiikka', *Sosiaalilääketieteellinen Aikakauslehti*, 28 (1991): 197–206; see also Bernard Williams, *Moral Luck: Philosophical Papers 1973–1980* (Cambridge: Cambridge University Press, 1981), Chapter 5; James D. Wallace, *Moral Relevance and Moral Conflict* (Ithaca: Cornell University Press, 1988), Chapter 1; Peter Singer, *Practical Ethics*, 2nd edition (Cambridge: Cambridge University Press, 1993).

<sup>2</sup> Søren Holm, 'There Is Nothing Special about Genetic Information'. In Thompson, Alison K. and Chadwick, R. F. (eds.), *Genetic Information: Acquisition, Access, and Control*. Kluwer Academic/Plenum Publishers, New York, p. 97.

# The Prerequisites for Genetic Democracy

Helena Siipi

## 1 Introduction

### *1.1 What is Genetic Democracy and Why does it Matter?*

Traditional forms of representative democracy have been considered insufficient in many contexts concerning new gene-technologies. In Europe, Directive (2001/18/EC) on the deliberate release of genetically modified organisms (GMOs), for example, widens citizens' opportunities for public participation by stating that the public must be consulted when GMOs are grown outside laboratories. At the same time, citizens' freedom of choice concerning their personal lives has been strengthened, for example, by the labeling requirement of genetically modified food.

Yet, tendencies towards limiting citizens' control over new gene and biotechnologies can also be detected. Strict restrictions control the applications of much gene-technology: genetically modified crops and gene therapies, for example. Moreover, the creation of biobanks based on broad or presumed consents imply a decrease of citizens' control over what control is in other analogous contexts. A biobank based on broad or presumed consent gives a citizen much less control over the use of his or her tissue sample than does a traditional research in which tissue samples are collected for specific purposes and informed consent asked.<sup>1</sup> Thus, it is justified to say, that in the context of new gene-technologies, the practices of democracy are being modified.<sup>2</sup> The ethics of these modifications and their outcomes is the topic of this paper. To put it more strictly, the prerequisites for genetic democracy are discussed.

Broadly taken, genetic democracy means democracy with respect to gene-technologies. In a state of genetic democracy, research, development, and the application of new gene-technologies happen according to the ideals of democracy. The term 'genetic democracy' can, thus, be understood as an abbreviation for 'the democratic use of new gene-technologies'.

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H. Siipi  
University of Turku, Finland  
e-mail: helsii@utu.fi

The issues surrounding the prerequisites for genetic democracy are socially central and important, since it has been predicted that gene-technology will play a major role in Western societies in the near future.

The next societal phase after the Information Society is already in its embryonic state. Biosciences, biotechnology, gene therapy, etc. are gaining more and more influence in research, technology, everyday life and societal development. Within a decennium it probably makes sense to speak of *Biosocieties* instead of Information or Knowledge-intensive societies in the highly developed Western world.<sup>3</sup>

The qualitative emergent features of the Biosociety will most probably be related to our knowledge of genetic features of living beings, like plants, animals and of course human beings as one species of animals. They will also be related to how to use this knowledge in preventing and curing severe diseases, in manipulating the genetic code of living beings in e.g. producing genetically modified food (GMO), and maybe in altering physical and even mental attributes of human beings, and finally in industrial processes.<sup>4</sup>

Although similar statements have been widely presented,<sup>5</sup> others have suggested that gene-technology will not play such a central role in future societies.<sup>6</sup> Yet, even if the critics turn out to be right, questions related to genetic democracy may be crucial, quite simply because many people *believe* that gene and biotechnologies will be central factor in future society. In the Eurobarometer 2005, for example, some 52% of people thought that gene and biotechnologies will improve our way of life over the next 20 years and some 12% judged that they will make things worse. Some 22% did not know whether gene and biotechnologies will have effect on their lives and only 13% thought gene and biotechnologies will have no effect on their lives.<sup>7</sup> As long as this many people believe in great social effects of gene and biotechnologies, it is ethically necessary to pay attention to genetic democracy. To be more precise, we need to know what is needed to achieve genetic democracy. What are its prerequisites?

## ***1.2 Democracy and Genetic Democracy***

As the above characterization of genetic democracy as democracy with respect to gene-technology implies, genetic democracy is closely related to democracy in the more general sense of the term. The term ‘democracy’ is originally Greek and it means that people rule.<sup>8</sup> Nevertheless, this ‘ruling’ may happen in numerous difference ways and the term ‘democracy’ is today used in variety of different contexts and in a variety of different senses. The term may denote western liberal democracies, socialist states or the city-states of ancient Greece, for example.<sup>9</sup> Moreover, the term is used in both a descriptive as well as in a normative sense.<sup>10</sup> Finally, even when the term is used in a normative sense in the western liberal context – as is the case in this paper – determining what is required in order to achieve democracy is not always clear.<sup>11</sup>

Nevertheless, some ideals or basic requirements for democracy are shared by the majority of theories. I will discuss four such ideals with respect to genetic democracy: effective participation,<sup>12</sup> equality,<sup>13</sup> autonomy,<sup>14</sup> and transparency.<sup>15,16</sup>

The prerequisites for genetic democracy are intimately connected with these ideals, although the prerequisites cannot be deduced from them. Rather, the prerequisites should be understood as interpretations of the four ideals in the context of gene-technologies in western liberal societies of today. The presented prerequisites of genetic democracy are, thus, defended by closely connecting them to generally accepted ideals of democracy. The process of forming the prerequisites is, nevertheless, two-way since the context of gene-technologies does not only have its effects on interpretation of the ideals, it also determines that the four ideals are regarded as central.

## **2 Effective Participation and Public Engagement**

In a democracy people have possibilities to participate effectively.<sup>17</sup> In other words, in democracies people have opportunities to make their views known and thus influence the decisions on issues belonging to public sphere. The minimum requirement for effective participation is that all citizens have right to vote in competitive elections.<sup>18</sup> However, many theorists criticize this minimalist conception of democracy; they understand democracy as implying other ways of affecting public decisions as well. Deliberative theories of democracy, for example, emphasize the role of discussion in decision-making. In ideal cases, solutions are found by rational discussion and deliberation, and no voting is necessary at all.<sup>19</sup>

In genetic democracy, the focus is not so much on voting procedures but rather on deliberative and interactive parts of democratic processes. Instead of focusing on individual citizens who have a vote to cast, the emphasis is on citizens as social beings and on more interactive forms of participation. According to the latter view, in gene-technological issues decisions can be reached not only by voting, but also by debate and deliberation.<sup>20</sup> Moreover, these interactive means may promote the quality of decisions and thus serve as a means of achieving better solutions. In practice, this emphasis implies that the public is engaged in decision-making concerning the new gene-technologies not by raising them as a theme in elections, but rather by involving people in decision-making at the grass-root level.

Public engagement contributing to genetic democracy should not be confused with other activities often termed 'public engagement'. The term 'public engagement' is commonly used to refer to procedures which are designed to increase public involvement with scientific issues rather than enabling them to participate in decision-making practices. The latter can be regarded as forms of public informing or even as lobbying for gene-technologies. The logic behind the solution to diminish public engagement to information giving is that controversies concerning new gene-technologies are based on lay people's lack of knowledge and misguided fears. Those who support such views assume that when people learn more about gene-technologies, they will also accept them and agree with scientists and decision-makers about the way technologies should be used and developed.<sup>21</sup>

The view that informing the public is sufficient to satisfy the requirements of public engagement is, however, mistaken. First, more information about gene-technologies does not always lead to greater agreement about their moral acceptability. On the contrary, information may even lead into more criticism.<sup>22</sup> Moreover, the view of scientists and lay people as opposing parties is too simplified. Not all scientists and experts accept all or most gene-technological applications, nor are all or most lay people are critical towards them. Neither scientists nor citizens form a uniform mass.<sup>23</sup> Even claiming that all or even most lay people are either for or against gene-technologies is too simplistic. Many citizens may have no interest in the ethical features of technologies, some may be unable to decide, and even those who hold strong views about certain gene-technological applications do not necessarily hold categorical for or against views concerning gene-technologies in general. Moreover, people presenting critical questions about some uses of gene-technology may, nevertheless, be willing to acknowledge merits of those and other gene-technologies.<sup>24</sup>

Most importantly, public engagement that consists of merely informing the public is from the point of view of democracy insufficient. That kind of public engagement gives citizen's only quite indirect opportunities to affect decisions.<sup>25</sup> People are regarded to be passive receivers of information and new technologies, whereas, according to the requirements of democracy, they should have possibilities to affect the ways the new technologies are used and developed. Labelling public information campaigns, and even attempts to control public opinion, as 'public engagement' does not suffice for democratic way of action.<sup>26</sup>

In the context of gene-technologies, the possibility of effective participation has been actualized in practice through public hearings, consensus seminars, citizens' juries, public opinion surveys, and the use of focus groups in decision-making, for example. However, even these methods may fail to fulfill the requirement of the possibility for effective participation. Even though they offer procedures by which citizens can affect certain decisions concerning gene-technology, the role of initiator is still left to the decision-makers. In other words, decision-makers still determine the time and matters (i.e. topics) of public decision-making. Yet, as Maija Setälä points out, democracy presupposes not just the possibility to participate in decision-making, but also the possibility to participate in determining the questions on which decisions are made and on what alternative solutions are set for those questions.<sup>27</sup> In other words, the public must also be able to participate in forming of the political agendas.

In the context of genetic democracy, possibility for effective participation is interpreted as meaning that individuals and groups are free to express their opinions on issues related to the new gene-technologies – even if the view is non-scientific or based on an emotional response. Moreover, and most importantly, everybody has the right to be heard.<sup>28</sup> This means that channels by which citizens can inform decision makers (and sometimes also scientists) about their views concerning new gene-technologies must be created. The right to be heard is not restricted to the cases where decision-makers want to find out the public opinion, rather it concerns all contexts of use, application, and development of gene-technology. Thus, the

prerequisite for the possibility of effective participation raises questions that concern its practical realization. What kinds of procedures can guarantee that citizens are really heard? How should the lay views expressed be taken into account? When should decision-makers seek consensus and when should they allow the majority to decide? These are all questions which must be answered before the prerequisite of public engagement can be deemed adequately in place.

### 3 Equality and Non-discrimination

Democracy presupposes certain equality between citizens. Citizens do not need to be equal in all possible respects – for example in terms of their finances. However, in the state of democracy, they may not be unequal in certain important senses that concern decision-making in public matters.<sup>29</sup> What is important is political equality: equality in terms of citizens' opportunities to influence political decisions. In minimum, democracy presupposes voting equality between citizens.<sup>30</sup> As Rober A. Dahl puts it, '[w]hen the moment arrives at which the decision about policy will finally be made, every member must have equal and effective opportunity to vote, and all votes must be conducted equal'.<sup>31</sup> Moreover, the election system itself may not favour any particular party or candidate.<sup>32</sup>

However, since many decisions concerning science and technology are not political (or legal) but rather ethical, and since genetic democracy to great extent focuses on deliberative and interactive parts of democratic processes, equality must present itself in some other way. In the context of genetic democracy, the ideal of equality can be best characterized as *non-discrimination of interests and values*. Non-discrimination of interests and values implies that all individuals, groups and values systems related to gene-technology are given a due attention. No view is labeled senseless or irrelevant from the beginning. Moreover, no point of view is to be considered more urgent than others without due cause. Bioscientific views, for example, do not categorically override social and ethical considerations.<sup>33</sup> Rather different points of views and considerations are closely examined in the decision-making process in order to determine the impact they should have on the ultimate decisions.

Value pluralism is accepted in genetic democracy. Different individuals and groups hold different values as fundamental, and these differences are respected and taken into account in policy making.<sup>34</sup> Moreover, public discussion and arguing over gene-technological issues are regarded as being desirable and valuable. In a state of genetic democracy, there may be a multidimensional, lively, ongoing public and academic discussion about gene-technologies. People may even be encouraged to participate in such deliberations. When decisions are made, a diverse range of views are heard in a manner that is responsive to different expert and lay public views.<sup>35</sup> Experts, for example, may not give voice to lay people's thoughts, since these groups are often concerned with different questions.<sup>36</sup>

The prerequisite of *non-discrimination of interests and values* raises questions as to how it should be applied in practical decision-making. Non-discrimination of

interests and values implies that citizens and their views should be taken seriously, but what this means in the context of policy formation and the science of new gene-technologies is unclear. For example, who should decide what criteria should determine whose views carry most weight? In other words, how should decision-makers determine which views are accepted as the most relevant, appropriate and correct ones? The weight that common but scientifically unsound views should have in biotech decision-making needs also be determined. Moreover, it needs to be asked, under what conditions may scientific views override non-scientific ones and vice versa. What role should be given to affective views?

## 4 Autonomy and Freedom of Choice

The ideals of effective participation and equality presuppose citizens' freedom and autonomy. Participation without freedom of choice is only apparent. 'Participation' in which people are coerced to promote certain issues is not participation in the real sense of the term, nor is it either socially or ethically valuable. Similarly, equality in which everybody is coerced in strong, yet equal, sense is not socially or ethically desirable. Thus, autonomy and freedom of choice form the third ideal of democracy.

[A] properly democratized state will necessarily be freedom friendly: the coercive actions it takes will not offend against the freedom of those coerced, or at least no offend in the manner of coercion by a private agent or an undemocratic state.<sup>37</sup>

Even in democracies, governments can restrict the range of activities in which people can enjoy freedom (for example, democracy does not imply that people should enjoy the freedom to damage property or others). However, in democracies governments tend not to violate freedom: they may place conditions on people's freedom, but not compromise it.<sup>38</sup> In other words, in democracies freedom and the autonomy of citizens is restricted only in order to protect the equal freedom and autonomy of other citizens. Since all citizens should have the freedom to walk safely in the street, for example, all citizens' freedom to attack other citizens walking in the street is strongly restricted. Moreover, in a democracy everyone (or at least every adult) is assumed to be autonomous in the sense of being the best judge of his or her own goods and interests. Thus, strongly paternalistic authority is – with rare exceptions – not accepted in democratic states. People should be free to make their own decisions on matters that primarily concern themselves.<sup>39</sup>

Thus, in the context of genetic democracy, autonomy and freedom of choice mean that citizens should not be forced to use new gene-technologies in their personal life against their wishes. This third prerequisite of genetic democracy has been much discussed with respect to labeling of genetically modified food<sup>40</sup> and patients' freedom of choice concerning genetic treatments.<sup>41</sup> However, autonomy and freedom of choice are not solely concerned with the use of technologies; public participation related to those technologies is also an issue. In genetic democracy, people have freedom of choice as to whether or not they participate in public engagement procedures related to new gene-technologies.

In the context of gene-technologies, freedom of choice has usually been interpreted as a negative right – that is as the right to avoid using gene-technologies if one so wishes. It may, nevertheless be asked, whether autonomy and freedom of choice sometimes imply a positive right – an access to technology if one so wishes.<sup>42</sup> Moreover in needs to be found out, what, besides lack of coercion is required for autonomy and freedom of choice.

## 5 Transparency and Informing Public

The ideal of freedom and autonomy is intimately connected to citizens' access to the relevant information. Freedom of choice concerning gene-technologies lacks value, if citizens cannot have information about different gene-technological alternatives. Even though choice made without relevant information about different technologies might be free in some restricted sense of the term, this kind of freedom does not serve the interests of the general public. Moreover, the ideal of public participation presupposes that the public is sufficiently informed. People must be able to know about the issues on which they are allowed to participate. As Robert A. Dahl explains,

democracy has usually been conceived as a system in which “rule by the people” makes it more likely that the “people” will get what it wants, or what it believes is best, than alternative systems like guardianship in which an elite determines what is best. But to know what it wants, or what is best, the people must be enlightened, at least to some degree [. . .] [Thus,] each citizen ought to have adequate and equal opportunities for discovering and validating [. . .] the choice on the manner to be decided that would best serve citizen's interests.<sup>43</sup>

Thus, the fourth ideal of democracy is transparency. Democracy implies access to correct and relevant information on matters that are the subject of public, and sometimes even personal, decision-making. Citizens have the right to know what is being *planned* in the field of science and technology. Moreover, they should have access to information concerning what has been *decided* by legislators and public authorities. Not just the final decisions, but also the reasons why those decisions were made should be available to the public.<sup>44</sup> Moreover, people should require information concerning the *implications* of these decisions and plans. People should to certain extent be informed how the plans, if carried out, and decisions affect their life and society in short and long term.

Transparency does not imply access to any kind of information; rather it is concerned with the availability of *adequate* information. This restriction implies several things. First, information given to citizens should, as far as possible, be correct, non-biased and relevant to the issue in question. This requirement is easy to accept in principle, but it may prove difficult to achieve in practice since it assumes that there is consensus on who should be trusted as the holder of correct and non-biased information. In practice, information given to public must be chosen from a large set of information. Moreover, it is chosen by somebody who understands the goals of informing. Yet, what should these goals be? And who should carry out the choice

process? Moreover, it needs to be asked whether informing should be carried out actively or passively. In other words, should adequate information be actively provided to citizens for example by the mass media, or is it sufficient just to provide them an access to information like records and minutes?

Second, the requirement of adequacy may set limits to the information to which citizens and interested groups have access. Some information, for example certain types of business secret, may be kept confidential. What is important is that people have access to information that is relevant to them when making choices about their social and personal lives. Third, citizens and groups have not just the right to acquire but also an obligation to provide only adequate information. The requirement of adequacy is not only concerned with the only information provided by decision makers and scientists, but also with that provided by citizens and citizen groups. They also have the responsibility to follow the ideals of correctness, relevance and being non-biased.

## 6 Conclusion

Since many people consider gene-technology an integral part of future society, discussing issues related to genetic democracy is important. The ideals of democracy are intimately connected to the prerequisites for genetic democracy. In this paper, I have presented that connection with respect to four ideals and prerequisites. However, as the presented questions in discussions concerning each prerequisite indicate, the prerequisites are too general to determine the right ways of action in all concrete situations. Even after the identification of prerequisites many practical questions about genetic democracy are left unanswered. Yet, I hope that the presented prerequisites of genetic democracy can function as a theoretical basis on which ethical questions on genetic democracy can be discussed. Ideally, they will form a bridge between democracy in general and the practical questions related to socially acceptable ways of using new gene-technologies.

## Notes

<sup>1</sup> See for example Arnason [2004] and Chadwick [2001]. Donating tissue to research on a specific issue (e.g. diabetes) ensures much more control over the use of one's tissue sample than can be achieved when by donating tissue to a biobank. This is because the research projects for which the donated tissues will be used are not known at the moment tissue is donated. Ruth Chadwick (2001, 205–206) discusses biobanks and the concept of broad consent. In her case, this meant that donors gave their consent to the biobank in question to use their donated tissue in any future medical study. Vilhjálmur Arnason [2004] discusses Iceland's biobank where consent is 'presumed'; that is, the donors have not formally given their consent but the biobank believes they would give it if asked.

<sup>2</sup> These modifications are, of course, also results of the democratic process.

<sup>3</sup> Mannermaa (2003, 14).

<sup>4</sup> Mannermaa (2003, 16).

<sup>5</sup> See for example Ahlqvist (2005, 503); Kuusi [2004] and OECD (2006, 1–2).

<sup>6</sup> See for example Tamminen [2004].

- <sup>7</sup> Gaskell (2006, 10).
- <sup>8</sup> Harrison (2001, 3); Setälä (2003, 18) and Birch (2001, 71).
- <sup>9</sup> Harrison (2001, 3–5) and Dahl (1989, 30).
- <sup>10</sup> Setälä (2003, 10).
- <sup>11</sup> For further discussion see, for example, Setälä (2003); Dahl (2000); Harrison (2001) and Birch (2001).
- <sup>12</sup> Dahl (2000, 37); Setälä (2003, 26–27) and Birch (2001, 104).
- <sup>13</sup> Harrison (2001, 177); Dahl (1989, 37) and 2003 (2003, 79).
- <sup>14</sup> Harrison (2001, 162); Birch (2001, 119); Petit (1999, 163–164) and Dahl (1989, 100).
- <sup>15</sup> Dahl (1989, 111–112); Setälä (2003, 131) and Dahl (2000, 37).
- <sup>16</sup> See paragraph two for effective participation, paragraph three for equality, paragraph four for autonomy, and paragraph five for transparency.
- <sup>17</sup> Dahl (2000, 36).
- <sup>18</sup> Przeworsky (1999, 23) and Setälä (2003, 60).
- <sup>19</sup> Setälä (2003, 131–132).
- <sup>20</sup> Similar tendencies can be seen with regard to public participation in environmental issues (for them see Rydin 2006, 3).
- <sup>21</sup> Moroso (2006, 15); European Federation of Biotechnology (2003, 3) and Marris et al. (2001, 76).
- <sup>22</sup> O’Neill (2002, 11); Paula and Birrer (2006, 261); European (2003, 4).
- <sup>23</sup> Marris et al. (2001, 79).
- <sup>24</sup> Marris et al. (2001, 79).
- <sup>25</sup> In a democratic system, the public’s right to information can affect the content of decisions. Decision-makers favour decisions that the general public can accept.
- <sup>26</sup> This is not to say that providing information is not central to genetic democracy. As will be shown, democracy limits acceptable forms of providing information.
- <sup>27</sup> Setälä (2003, 27).
- <sup>28</sup> For similar views see for example Sterckx and Macmillan (2006, 219); Davis (2001, 78) and Karlsson (2003, 51).
- <sup>29</sup> Dahl (1989, 98).
- <sup>30</sup> Setälä (2003, 79).
- <sup>31</sup> Dahl (2000, 37).
- <sup>32</sup> Setälä (2003, 79).
- <sup>33</sup> These views may not even be mutually compatible.
- <sup>34</sup> Dodds and Thomson (2006, 331).
- <sup>35</sup> Dodds and Thomson (2006, 327, 330) and Braun (2005, 44).
- <sup>36</sup> Röcklinsberg (2006, 289).
- <sup>37</sup> Petit (1999, 163).
- <sup>38</sup> Petit (1999, 164).
- <sup>39</sup> Dahl (1989, 100).
- <sup>40</sup> See for example Klombenhower and van den Belt (2003); Launis (2003, 127–128) and Rääkkä and Rossi (2002, 37–39).
- <sup>41</sup> See for example Cahill [2003] and Buchanan et al. [2000].
- <sup>42</sup> For more on positive and negative rights see for example Buchanan et al. (2000, 207–208).
- <sup>43</sup> Dahl (1989, 111–112).
- <sup>44</sup> Resnik (2001, 186) and Sharpe (2002, 24).

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# Ethical Expertise in Democratic Societies<sup>1</sup>

Eerik Lagerspetz

## 1 On Ethical Expertise in Democracies

Most political decisions made by legislators and other elected officials have an ethical dimension. The traditional ideal of good government, powerfully formulated by Plato, is that it is a government of ethical experts. Some people are experts in medicine: they should make the decisions in which the medical aspect is predominant. Some people are experts in ethical issues: they should decide on issues which are primarily of ethical nature.

However, modern societies are democracies. And the theory of democracy is generally incompatible with the idea of publicly recognised ethical expertise. This does not imply that democracy has to be based on ethical scepticism or relativism. We may admit that the common good is a matter of knowledge. We may also admit that, in principle, some people may have better knowledge about it than others. Thus, we may admit the possibility that some people are “moral experts” in the sense that they are wiser in moral issues than the rest of us. The problem is, however, that there is no agreed way to *recognise* who is a moral expert. Therefore, such knowledge cannot legitimate any claims to political authority. In moral issues, there is no general consensus about ends. Thus, there can be no inductive arguments for moral expertise, for if we disagree on the ends, we also disagree on how well the supposed experts are capable of realising the proper ends. As David Estlund<sup>2</sup> says, claims to political authority should be backed by a justification that could be accepted by “all reasonable people”. Without a consensus on the ends we have no inter-subjective way to evaluate the evidence we have. We can formulate a quasi-transcendental argument against the epistemic justification of the regime of moral experts. If there were genuine, recognizable forms of moral expertise, all morally important decisions should be made by experts only. Now, the choice of an expert is *itself* a morally important decision. Indeed, it is likely to be the most important of all decisions, for by choosing wrong experts we are likely to get wrong decisions.

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E. Lagerspetz

Professor of Practical Philosophy at the University of Turku, Finland  
e-mail: eerlag@utu.fi

By the argument, this decision should *also* be made by experts, etc. We are in a regress. The conclusion is that even if the common good is something independent and knowable, the only generally justifiable way to find out what it requires is to rely on democratic mechanisms. This view alone seems both to explain and justify our democratic practices. Democracy is (partly) a process in which views and hypotheses about the nature of the (common, social) good are formulated, discussed, accepted, and revised. We have seen that democratic theory is generally incompatible with the idea of publicly recognised ethical expertise.

However, even in democratic societies some people are officially empowered to deal with the ethical aspects of various issues, although their position is far removed from that of Platonic philosopher-kings. In Western societies, there is an increasing number of Ethics Councils and similar bodies. These bodies are supposed to give ethical advice, but sometimes also to make binding decisions. Given the pro-democratic argument above, how should we understand the role of these limited forms of ethical expertise in democratic societies? What are these ethical advisers doing? How do they themselves see their own role? And what *should* their role be in a democratic society? How they should make their decisions? These questions are not only of philosophical nature; they require empirical research, and there is surprisingly little available. Nevertheless, philosophers may also have something to say about these matters. Ethics Councils and similar expert bodies are themselves partly products of academic (applied) philosophy. Their existence is justified by the philosophical idea that ethical discussion and ethical decision-making are partly autonomous, not reducible to legal, political and technical-scientific practices. What I am advocating here is *reflexive applied ethics*; by this fashionable-sounding phrase I mean ethical study of those practices and institutions which themselves derive their justification from applied ethics.

Legislators are, of course, bound by ethical considerations. But in a democracy, the authority of legislators has a separate, procedural source of legitimacy. Legislators are elected by the people, and are, at least in principle, politically responsible to their constituents. The legitimacy of courts is also derived from the legitimacy of democracy: their task is to interpret laws which are enacted in a democratic way. While being free from direct political responsibility, judges are subjects to professional bureaucratic responsibility. They are recruited on competence basis, and they can be dismissed if they are not sufficiently competent. The content of their competence is defined by the law. Finally, the power of scientific experts is based on the legitimacy of their scientific disciplines. Generally, someone has a right to act as a medical expert only if she is accepted as a medical expert by other medical experts. But there is no vicious circle in the justification of the authority of medical experts. For although we laymen cannot recognise medical expertise without relying on the recognition of other experts, medical science as an institution is ultimately legitimated by its consequences: if the doctors can really help us, they generally (not always) know what is best for us. The effectiveness of medical practices is not, at the end, a medical question. Medical science as an institution is legitimated in an inductive way. Thus, in medicine, unlike in politics or in moral matters, (a) there is generally a consensus about the end or the ultimate value and (b) there

can be inductive evidence, ascertainable to all rational persons sharing the end, that by accepting certain practices as authoritative they may, in the long run, do better than by not accepting them. Consequently, if there is no consensus about ends, or if experts strongly and persistently disagree on their recommendations, their authority in those issues is undermined. Unlike courts or parliaments, scientists cannot resolve their disagreements by taking vote.

The point of these observations is simply to show how that the authority of ethical experts is more like that of a judge than that of a scientist. Politicians, judges and scientific experts may, at least sometimes, appeal to their background legitimations when justifying unpleasant decisions. “Personally I would like to see Finland as a member of NATO, but in a democracy, we have to follow the will of the majority in the Parliament.” “You might not be happy with the verdict, but that is what the law says.” “I conclude that the greenhouse effect is a scientifically established fact whether you like it or not.” When challenged, ethical experts cannot, unlike politicians, appeal to the ultimate authority of a procedure. Nor can they appeal to ethical facts which hold independently of shared opinions. Even if there are such facts, ethical experts cannot claim that they possess a superior method of finding out what the ethical facts are. The only thing they can appeal to, beyond their personal convictions, is the *shared* morality: “I am willing to stop all kind of experimentation with animals, but the people are not ready for that. As a member of this board, I can only do my best to prevent unnecessary painful and needless experiments.” This is an appeal to a positive fact, to the *shared* morality.

Why do we need ethical expertise? One possible answer is that the task of ethics councils and similar bodies is simply to fill the gaps left by law and/or factual considerations. According to this view, if we had enough empirical knowledge and if the relevant legislation were sufficiently detailed and based on adequate information, there would be no need for specific ethical expertise. The relevant ethical issues could be resolved either at the legislative level or at the level of legal interpretation. This is a possible position. It might be supported by the following argument. “If the issues dealt with the ethical experts are not inherently problematic or controversial in the relevant society, they could be resolved without any special ‘ethical’ expertise. If they are inherently controversial, ethical experts have no special authority over them. In principle, the only way to solve inherently controversial value issues is the democratic way. But issues are complex; new issues arise continuously; the law is never sufficiently precise, complete and update; legislators and judges are never sufficiently informed. Therefore, it may be better that these issues are dealt with a special body – let’s call it ‘ethical’ if you like. But let’s not pretend that it has a privileged access to some special kind of ethical knowledge.”

I think that there is more to be said about the role of ethical expertise. And I also think that “reflexive applied ethics” is most plausibly conceived as a branch of normative political and legal philosophy rather than as a branch of “ethics” in a more restricted sense. In the remaining part of this paper, I am mainly relying on one single classic of legal philosophy – H. L. A. Hart’s *The Concept of Law* (1961) – and on my own study on that work.<sup>3</sup> Although Hart’s book is justly recognised as

an important work on legal philosophy, I have always read it in a wider context, as an interesting (and surprisingly rich and complex) study on human society in general.

## 2 A Hartian Treatment of Ethical Expertise

In his work, Hart makes the distinction between *positive* and *critical* morality. These expressions do not refer to different types of moral reasons. Rather, they refer to a single phenomenon seen from different *points of view*. Let us consider the following example. A convinced defender of animal rights argues that “there is” a moral reason not to use animals in genetic research. By making this claim, he is not arguing that such reason is generally followed in the society he lives, or that when animals are used in experiments a serious criticism is usually forthcoming, or that most people accept his claim as valid. In some societies, he might well be almost the only person holding that opinion. Nevertheless, he insists that “there is” an obligation not to make experiments with animals, not only that it would be a good thing if people generally followed his personal ideals. The reason in question is a part of the activist’s critical morality. In most societies, experiments with animals are allowed; at the same time, certain ways to treat animals are strictly prohibited, not only by law but also by shared morality. For example, both the animal right defender and the average citizen may agree that there is a moral reason not to allow cockfights. Both for the animal right activist and for Mr. Average, this is a genuine moral obligation which legitimates critical reactions against those who do not follow it. Thus, the rule against cockfights is part of their critical morality. But because it is also a generally shared moral reason, it can be seen as a part of the positive morality of the relevant society.

Although there are several types of moral reasons, obligations or duties are paradigmatic moral reasons for Hart. An obligation or duty is a part of the positive morality of some society if and only if (i) people are generally required to do or abstain from a given act upon specific occasions, (ii) people generally obey the requirement; (iii) they obey it because they generally consider it morally important – it is part of their critical moralities; (iv) deviation from the requirement is generally considered a good reason for critical reactions; (v) these reactions are expressed in moral language, and (vi) these conditions (i–vi) are common knowledge in the relevant society. These conditions are sufficient to distinguish the requirements posed by the positive morality from those of etiquette, habit, and law, as well as from those of prudence, personal maxims, and general ideals.

For most of the time, our lives are mainly guided by the requirements positive morality. We apply it at home, or when standing in a queue, or in a shipwreck. “Don’t disturb your neighbours at night”, “First come, first served” and “Children and women first” are neither personal moral principles nor legal requirements. They are non-legal, generally shared rules of human conduct in a society like ours. They tell us how things are done, how we are expected to behave. They are Hartian social

obligations. Most of us accept them as genuinely binding; the rest of us obey them because we are (hypocritically) afraid of critical reactions. It is clear that our shared life requires the existence of a positive morality. In a sense, law has a secondary role and is likely to be relevant only in certain issues. (Although I refer to Hart, a reference to Hegel might be equally appropriate: his *Sittlichkeit* is another idealised description of the same phenomenon).

As a philosopher of law, Hart tries to give an account of the role of law in human life. He tries to show why positive morality is not enough, why we need law. Consider a “Lockean” state of nature governed by positive morality only. There people have to face three problems. First, the critical reactions related to an obligation can guide people only if the critical reactions are sufficiently coordinated. When the enforcement of obligations is a task of individual members of the society, some transgressions may remain un-enforced while in other cases there are overreactions. There should be further requirements saying who should enforce the primary requirements, and when and how it should be done. Second, there will be disagreements and problems of interpretation. A third party may be set to solve the disagreements; but such an umpire has to be put under further requirements which, in their turn, have to be interpreted and enforced. Third, a regime of positive morality tends to be too static. When external circumstances change, the same social values could perhaps be realised in a better way by adopting a new rule. Or, then, the shared social values may themselves change. Somebody has to initiate the change of rules, and the content of new rules should be effectively communicated to the members of the society. According to Hart, these problems related to positive morality help us to understand why law is needed. Law contains *rules about rules*: rules which say how the primary duties are enforced, interpreted, and changed. Moreover, in a developed legal system, these secondary rules have to have a reflexive character: rules of enforcement, interpretation and change are themselves enforced, interpreted and changed. All this is impossible under a static regime of positive morality. Institutionalization is the central property of law: institutionalization makes it at the same time more predictable and more flexible than the positive morality.

In this view, law is ultimately a form of institutionalized morality. This may sound paradoxical. After all, Hart is usually considered the leading legal positivist, and, at least in introductory texts, a strict separation between law and morality is presented as a defining property of legal positivism. However, there is no contradiction. Law is a form of morality in the sense that it is an institutionalised form of *positive* morality. This judgment is made from the external point of view, to use the Hartian term. From the external point of view, something could be described as “moral” without making a corresponding critical moral judgment; when we say that morality, as well as law, forbids abortion in some strictly Catholic countries, we are not making a critical judgement against abortion. Hart’s point is that normative expressions – “moral”, “ought”, “should not”, “obligatory”, “permitted”, “right” and so on – may be used in different ways. They can be used to criticise, praise and approve actions, persons and states of affairs. They can also be used to describe moral and legal practices existing at a certain time in a particular society. When normative expressions are used in a descriptive way, the presupposition is that there

are others who, in the same cases, use them in the evaluative or prescriptive way. If I say “Abortion is forbidden”, meaning that it is forbidden by the law or by the prevailing morality of some society, I presuppose that the members of the society do generally use similar expressions in a prescriptive way in relevant situations (for example: in courts, when giving a moral or legal advice, when commenting other people’s actions or statements etc.). In this sense, law and legal language are inherently related to morality. But an answer to a question: “Is this allowed by law?” does not require a critical moral judgement, although it may require a descriptive judgment about the contents of positive morality.

How is all this related to the questions about the role of ethics councils and other ethical experts? One issue, not discussed by Hart, is that there may be *various degrees of institutionalisation of positive morality*. We may imagine a society in which there are rules for enforcement and/or for interpretation of the requirements of positive morality, and special bodies established for enforcement and/or interpretation, but no legislative bodies or rules for legislation. Historically, such intermediate normative systems have certainly been common. My idea is that ethics councils and other ethical experts with an official status can be seen as *interpreters of positive morality*. Their expertise is expertise about the content of the shared, prevailing non-legal requirements. The experts “know better”, not because they have a special access to some source of critical, correct morality. Rather, they are supposed to be experts in the sense that (i) they are aware of those (possibly conflicting) moral considerations which have wide support in the society, (ii) they know the relevant particular facts and (iii) being specifically nominated to perform the task of ethical judgment, they are under a duty to reflect the relevant considerations and facts carefully. They have no “legislative” powers. Consider the issue of animal experimentation. Suppose that an ethics council is expected to give general recommendations concerning the conduct of experiments. It may evaluate individual research proposals and perhaps refuse to accept some of them for ethical reasons. Hence, the council is interpreting and enforcing some rules, and these rules are not simply parts of law. The council is not, however, expected to pass a judgment on the ethical acceptability of animal experimentation in general. Unlike a legislative body, it cannot, by five votes against four, or even unanimously, decide that all such experimentation is immoral. It is expected to rely on such moral reasons that are *already* shared by many members of a society, or by a relevant subgroup of that society (say, by doctors). The council is most naturally seen as an interpreter and enforcer of pre-existing positive morality, useful when issues are complex and uncertain. Particular decisions may often be in conflict with the moral intuitions of many people, perhaps with those of the majority. But the background reasons behind controversial reasons must get support from a widely shared positive morality. In Hartian analysis such bodies are situated somewhere between fully institutionalised morality – law – and the shared morality applied in less specialised contexts. Consequently, their role is in some respects similar to that of courts. It should be noted that the positive morality interpreted by ethical experts is often codified in a quasi-legal way: there are written ethical codes and declarations which do not have a status of law.

Given the wide variety of positions taken by moral philosophers (or people in general), it is probably a good thing that ethical experts are generally constrained by the positive morality. From the democratic point of view, it would be problematic if moral advisers and decision-makers were allowed to follow their critical moral judgments only. (Consider a society in which all official moral advisers were strict utilitarians, or religious ethicists.) However, not all issues dealt by ethical decision makers can be subsumed under the reasons provided by positive morality. Again, we may refer to Hart. According to him, courts necessarily exercise *discretion*. This is due to the fact that most, perhaps all, central concepts in law are “open-textured”. Hart’s famous example is the interpretation of a simple sign “No vehicles allowed in the park”. Even such a simple prohibition may create difficulties of interpretation. Consider new motorised equipment for those having a moving handicap. Suppose that it is not just an ordinary self-moving wheel-chair, for it has a more powerful motor. Is it a “vehicle” in the relevant sense? The ordinary language may not provide any clear answer. The legal material may be equally inconclusive. Then, the interpreter of law – perhaps an ordinary police constable – has to exercise discretion. The interpreter himself may think that he is bound by some external standards, for example by those of morality. From an internal point of view, he is not free to decide whatever he likes. But from an external point of view, he supplements the law by non-legal considerations. Something similar may be said about ethical experts. The informed consent procedure in medical research on human beings may provide a parallel example. The traditional model is that, in any medical research on human beings, each subject must be adequately informed (among other things) of the aims and methods of the research. After ensuring that the subject has understood the information, the medical scientist should obtain the subject’s freely-given informed consent. The application of this principle would seem to make biobank-based epidemiological research practically impossible, since biobanks storing previously collected biological samples and genetic data are intended to facilitate mainly research projects that do not exist yet. Yet each research subject would have to be informed of the nature of the study and of the future use of the material collected. The key question is whether biobank-based research should be understood as medical research *on human beings* or merely as medical research on previously collected human biological material and data which can be conducted without a new informed consent. When trying to solve issues like this, ethical experts cannot just rely on the existing moral practices or on the “ordinary meaning” of expressions like “a human being”.<sup>4</sup> Although they cannot replace the requirements of positive morality by their critical judgments, they may supplement it when the reasons provided by positive morality have run out.

### 3 Conclusion

To repeat, why do we need bodies like ethics councils? One possible answer is the Aristotelian one:

For the many, of whom each individual is not a good man, when they meet together may be better than the few good, if not regarded individually but collectively, just as a feast to which many contribute is better than a dinner provided out of a single purse. For each individual among the many has a share of excellence and practical wisdom, and when they meet together, just as they become in a manner one man, who has many feet, and hands, and sense, so too with their character and thought. Hence the many are better judges than a single man of music and poetry; for some understand one part, and some another, and among them they understand the whole.<sup>5</sup>

According to the Aristotelian argument, ethical experts need not, *as individuals*, possess any “ethical” expertise beyond that possessed by the ordinary, adult, decent members of the society. Unlike judges, they are not expected to share a common intellectual perspective, resulting from common training. Unlike democratically elected representatives, they are not representing some particular, pre-defined perspectives. Rather, they are expected to be reasonable persons with different backgrounds and partly different perspectives to the shared, positive morality. As a deliberative group, they may be wiser than a single decision-maker, or a bunch of singular un-coordinated decision-makers who do not discuss with each others. And this may be the only solid basis for their claim of authority. The results may be better if difficult moral issues are first discussed in some group, *any group*, which is (i) sufficiently heterogeneous, (ii) well-informed in factual matters, (iii) not guided by a personal interest in matters at hand, and (iv) under a duty to take its role seriously. (In effect, this is a weak version of the epistemic argument put forth by Rousseau and de Condorcet).

The fundamental hypothesis behind this preliminary treatment of the role of ethical expertise is that *the role of ethical experts is (and perhaps should be) partly analogous to the role of courts and that similar concepts could be applied to both forms of decision-making*. This implies that a large part of the philosophical discussion on legal decision making is potentially relevant for an adequate “reflexive” theory on institutionalised ethical decision-making. What the legal philosophers have, and what the students of institutionalised ethical decision-making do not have, is a large and systematised corpus of empirical information. In order to understand what the role of ethical experts should be in a democratic society, we should first learn what they are actually doing. Most of the time, the ethical experts are probably doing good work. This does not mean that there is no need for critical ethical discussion on the role of ethical expertise in democratic societies. One important subject for future discussion is this: Given that ethical experts are generally performing their task well, how far such model could be extended?<sup>6</sup>

## Notes

<sup>1</sup> I am grateful to Veikko Launis and Juha Räikkä for their helpful comments and to Susanne Uusitalo for checking my English.

<sup>2</sup> See Estlund 1993.

<sup>3</sup> Lagerspetz 1995, especially Chapter 7.

<sup>4</sup> This example was supplied by Veikko Launis.

<sup>5</sup> Aristotle 1996, 1281b.

<sup>6</sup> For a recent work in ethical expertise, see e.g. Cowley, C.: 2005, "A New Rejection of Moral Expertise", *Medicine, Health Care, and Philosophy* 8, 273–279; Delkeskamp-Hayes, C.: 2005, "Societal Consensus and the Problem of Consent: Refocusing the Problem of Ethics Expertise in Liberal Democracies", in: Rasmussen, L. (ed.), *Ethics Expertise: History, Contemporary Perspectives, and Applications*. Dordrecht: Springer, pp. 139–161; Edwards, S.J.L., Ashcroft, R., and Kirchin, S.: 2004, "Research Ethics Committees: Difference and Moral Judgement", *Bioethics* 18, 408–427; Iltis, A. S.: 2005, "Bioethical Expertise in Health Care Organizations", in: L. Rasmussen (ed.), *Ethics Expertise: History, Contemporary Perspectives, and Applications*. Dordrecht: Springer, pp. 259–267; Nussbaum, M.: 2002, "Moral Expertise? Constitutional Narratives and Philosophical Argument", *Metaphilosophy* 33, 502–520; Powers, M.: 2005. "Bioethics as Politics: The Limits of Moral Expertise", *Kennedy Institute Ethics Journal* 15, 305–322; Veatch, R.M.: 2005, "The Roles of Scientific and Normative Expertise in Public Policy Formation: The Anthrax Vaccine Case", in: L. Rasmussen (ed.), *Ethics Expertise: History, Contemporary Perspectives, and Applications*. Dordrecht: Springer, pp. 211–225; Wear, S.: 2005, "Ethical Expertise in the Clinical Setting", in: L. Rasmussen (ed.), *Ethics Expertise: History, Contemporary Perspectives, and Applications*, Dordrecht: Springer, pp. 243–258.

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# Towards Global Bioethics: The UNESCO Universal Declaration on Bioethics and Human Rights

Henk ten Have

## 1 Introduction

On 19 October 2005 the 33rd General Conference of UNESCO, meeting in Paris, unanimously adopted the Universal Declaration on Bioethics and Human Rights.<sup>1</sup> This article explains the background, describes how the Declaration was developed, lists a number of its innovative provisions and examines the critical responses together with its possible impact.

When the United Nations Educational, Scientific and Cultural Organization (UNESCO) was established 60 years ago, its Constitution declared that peace must be founded upon the intellectual and moral solidarity of humanity. Julian Huxley, the first Director-General, pointed out that in order to make science contribute to peace, security and human welfare, it was necessary to relate the applications of science to a scale of values. Guiding the development of science for the benefit of humanity therefore implied “the quest for a restatement of morality . . . in harmony with modern knowledge”.<sup>2</sup>

Since its foundation, UNESCO has been concerned with moral issues in relation to science. From the 1970s onwards, the emergence of the life sciences, in particular, has led to international examination of bioethical questions. This global focus on bioethics was institutionalized in 1993 with the establishment of the International Bioethics Committee (IBC) with a work program and budget for international activities. The program was expanded in 1998 with the foundation by UNESCO of the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST), which is addressing other areas of applied ethics such as environmental ethics, science ethics and technology ethics. Since 2002 UNESCO has been coordinating the activities of international bodies in the area of bioethics through the Inter-Agency Committee on Bioethics of the United Nations (with, among others, FAO, OECD and WHO). In the same year, the 191 Member States decided that ethics should be one of the five priorities of the Organization.

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H. ten Have

Director of the Division of Ethics of Science and Technology in UNESCO, France  
e-mail: H.Tenhave@unesco.org

## 2 Standard-setting

One major objective of the work in ethics has been the development of international normative standards. This is particularly important since many Member States have only a limited infrastructure in bioethics. They lack expertise, educational programs, bioethics committees, legal frameworks and public debate. Technological progress, new knowledge and its applications, new diagnostics, preventive and therapeutic interventions, have significantly changed medicine and the life sciences as well as the context of health care, giving rise to bioethical dilemmas both in highly developed and less developed countries. Bioethics also is no longer the exclusive concern of scientists, medical professionals, or policy-makers. It concerns all people. Disease, disability, death and suffering are human experiences that sooner or later affect everybody. This is all the more true from an international perspective. Because of globalization, not only scientific and technological advances spread around the globe, but also bioethical dilemmas. As the example of cloning demonstrates, when a new technology has been developed in one country, it can be applied elsewhere, even if some countries want to ban its use. On the other hand, bioethical issues may arise because of inequality and injustice. If an effective medication for diseases such as HIV/AIDS, malaria and tuberculosis is available in some countries, it is morally problematic when patients die in other countries because of a lack of resources. It is not acceptable that research institutes and pharmaceutical companies carry out clinical trials in developing countries without applying the same standards of informed consent and risk assessment as in developed countries. The global character of contemporary science and technology and the increasing number of research teams coming from different countries imply the need for a global approach to bioethics. This is precisely what UNESCO aims to promote.

## 3 International Bioethics

In the past UNESCO has adopted two declarations in the field of bioethics: the *Universal Declaration on the Human Genome and Human Rights* (1997) and the *International Declaration on Human Genetic Data* (2003). The scope of standard-setting was expanded significantly with the mandate given by the Member States to develop a universal declaration on bioethics.<sup>3</sup> The previous declarations had focussed on the specialized area of genetics and genomics. When the new mandate was given, all topics relevant to bioethics were placed on the table for negotiation.

## 4 Building Consensus on International Bioethics

In October 2001, the General Conference, supported by the Round Table of Ministers of Science, invited the Director-General of UNESCO to examine the possibility of developing a universal instrument on bioethics. The feasibility study drafted by the

IBC concluded that it was possible to find common ground in divergent bioethical positions by focusing on basic principles.<sup>4</sup> Some of these principles had already been identified in previous declarations. The study also stressed the necessity to develop a universal instrument because scientific practices are now developing rapidly and extending beyond national borders. Developed and developing countries should therefore achieve broad consistency in regulations and policies.

In October 2003, the General Conference provided a mandate to submit a draft declaration in two years. In the meeting, the French President (Mr. J. Chirac) made a vigorous plea for a universal normative framework, preferably a Convention, to guide the progress of the life sciences and to protect the integrity and dignity of human beings. The subsequent process of drafting, entrusted to the IBC, taking into account the short time frame, the variety of ethical cultures and traditions, and the controversial nature of many bioethical issues, had four characteristics.

#### ***4.1 Gradual Elaboration***

To explore ideas about the scope and the structure, all Member States were consulted in writing between January and March 2004. The IBC organized a meeting in April 2004, inviting Intergovernmental Organizations (e.g. FAO, WIPO, Council of Europe), NGOs (e.g. WMA, HUGO), National Bioethics Committees (e.g. from Japan, Korea, New Zealand, Mexico, Republic of Congo) and international bioethics societies. Questions debated at this stage included whether the focus should be on human beings or broader; which fundamental bioethical principles could be identified; and whether specific areas of application of the principles should be explored.

#### ***4.2 Extensive Consultations***

Drafting the text between April 2004 and January 2005, the IBC extensively consulted many stakeholders. The UN Inter-Agency Committee on Bioethics discussed drafts during two of its meetings. Consultations with regional experts took place in Buenos Aires and Moscow. National consultations were held in the Netherlands, Iran, Lithuania, Turkey, Korea, Mexico, Indonesia and Portugal. In August 2004, the IBC organized a public hearing in Paris, with representatives of religious and spiritual perspectives. Finally, the draft text was subjected to a written consultation with all Member States between October and December 2004.

#### ***4.3 Transparent Process***

During the elaboration of the text, drafts, at various stages of the elaboration process, were published on the website of UNESCO. The work of the IBC drafting group was therefore conducted in as public a way as possible in order to facilitate consensus

formation and early identification of any dissenting views. During the 2005 General Conference many member states underlined the quality of the consultation process put in place for the elaboration of the Declaration.

#### ***4.4 Multiple Expertise***

Dealing with bioethics in an intergovernmental organization such as UNESCO implies a linkage between science and politics. Any normative instrument needs to reflect the scientific and ethical state of the art. But in the end it is submitted for approval to the Member States which then decide if they want to adopt it. The draft text developed by independent scientific experts of the IBC was necessarily subjected to political negotiations amongst the governmental experts who represented the governments of Member States. The result is that the cogency of the final text, in some respects, may be diminished in order to create maximum adherence by all of the governments involved. In order to facilitate the opportunities for compromise, the work of the independent IBC was connected at an early stage with that of governmental experts. Several amendments to the IBC text were made by the governmental experts. The Declaration, as adopted, represents the IBC draft as so amended.

### **5 The Contents of the Declaration**

One of the contentious issues in the elaboration was the scope of bioethics. At least three views were advanced. These were that bioethics has to do with (1) medicine and health care, (2) the social context, such as access to health, and (3) the environment. In different parts of the world, different conceptions, definitions and histories of bioethics are evident.

The scope of the adopted text of the Declaration is an obvious compromise between these views. It addresses “ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions” (Art. 1a).

The aims of the Declaration are multiple. However, the most important aim is to provide “a universal framework of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics” (Art. 2i). One characteristic of present-day bioethics is that it is not merely an academic discipline; it is also an area of public debate and policy-making. This is why the Declaration primarily addresses States. But at the same time, since the bioethical principles identified are founded on human rights and fundamental freedoms, every individual is involved in bioethics. The Declaration, therefore, also aims “to guide the actions of individuals, groups, communities, institutions and corporations, public and private” (Art. 2).

The heart of the Declaration is to be found in the 15 principles that are listed (see Annex). The principles determine the different obligations and responsibilities of

the moral subject (“moral agent”) in relation to different categories of moral objects (“moral patients”). The principles are arranged according to a gradual widening of the range of moral objects: the individual human being itself (human dignity; benefit and harm; autonomy), other human beings (consent; privacy; equality), human communities (respect for cultural diversity), humankind as a whole (solidarity; social responsibility; sharing of benefits) and all living beings and their environment (protecting future generations and protection of the environment, the biosphere and biodiversity).

Some of the principles are already widely accepted (e.g. autonomy; consent). Others have been endorsed in previous Declarations (e.g. sharing of benefits). What is innovative in the set of principles in the Declaration is the balance struck between individualist and communitarian moral perspectives. The Declaration recognizes the principle of autonomy (Art. 5) as well as the principle of solidarity (Art. 13). It emphasizes the principle of social responsibility and health (Art. 14) which aims at re-orienting bioethical decision-making towards issues urgent to many countries (such as access to quality health care and essential medicines especially for women and children, adequate nutrition and water, reduction of poverty and illiteracy, improvement of living conditions and the environment). Finally, the Declaration anchors the bioethical principles firmly in the rules governing human dignity, human rights and fundamental freedoms.

The section on the application of the principles (Arts. 18–21) is also innovative because it provides the spirit in which the principles ought to be applied. It calls for professionalism, honesty, integrity and transparency in the decision making process; the setting up of ethics committees; appropriate assessment and management of risk; and ethical transnational practices that help in avoiding exploitation of countries that do not have an ethical infrastructure.

## 6 Critical Responses

Although reflections on the Declaration are just beginning to appear, critical responses have focused on four issues: (a) the mandate of UNESCO, (b) the nature of the text, (c) the connection of bioethics and human rights, and (d) the primacy of individual values.

Concerns have been raised that with the Declaration UNESCO is “meddling in the professional domain of another United Nations (UN) agency, WHO”.<sup>5</sup> However, UNESCO is an organization of member states, like WHO. It is up to them to decide which organization deals with bioethics. Moreover, UNESCO has a strong involvement in bioethics since a decade. It has produced not only 3 Declarations in this area but also a long series of detailed reports of the IBC on various salient bioethical issues. UNESCO is the only UN agency with a mandate in science. Setting up a strong program in bioethics recognized the fact that many bioethical problems are connected with science and technology. The critical concerns do not acknowledge that UNESCO initiated cooperation with WHO (through the above Interagency

Committee) and that the standard-setting activities of both organizations are different (with WHO's guidelines being more technical). However, the concerns seem to reflect a different vision of bioethics, connecting it merely with health and medical issues rather than science and philosophy.

The nature of the text is sometimes misunderstood. It is criticized as having eliminated "all new obligations of states",<sup>6</sup> as a document characterized by minimalism and vagueness,<sup>7</sup> being produced by experts that are not really experts. But what is a weakness for some is a strength for others. Indeed in international law it is clear that a UN Declaration does not have binding force but nevertheless it "commands a certain respect".<sup>8</sup> Since the text is ultimately adopted by governments, it is the result of compromise. Underlying this second criticism apparently is a difference of opinion about what bioethics essentially is. Is it an academic discipline and "not the playground for government appointed politician-experts"?<sup>9</sup> This opinion ignores the history of bioethics in many countries where it is as much a public movement (emphasizing patient rights and public debate) and policy issue (resulting in health legislation and international treaties) as an academic discipline. It also reflects a dispute on the role of bioethics: is it primarily focused on studies interpreting some dimensions of the world or does it at least intends to change some dimensions (and thus being involved in policy-making)?

The third issue of critique focuses on the relationship between bioethics and human rights. The claim that human rights do not feature prominently in bioethics is not supported by facts; international documents such as the European Convention on Human Rights and Biomedicine, and the WMA Declaration of Helsinki refer to human rights (and human dignity). The UNESCO Declaration continues this appeal to human rights in establishing global bioethics principles. The connection with human rights was already made in the 1997 *Universal Declaration on the Human Genome and Human Rights*. Some scholars have recently pointed out that the Declaration's grounding of bioethics in universal human rights will bring international bioethics into a new phase of involvement with regulation and implementation, being accepted as part of international law.<sup>10</sup> Eventually it may be expected that the Declaration will become the starting point for an international bioethics convention.<sup>11</sup>

The fourth criticism questions the relationship between universal and culture-related values. It is argued that the Declaration, for example in Article 3, gives primacy to individual interests. Examining the listed principles, it is however remarkable that agreement was reached on a much broader range of principles, beyond the individually orientated ones. It is true that no hierarchy is given among the diverse principles. Article 3 nonetheless is remarkable since it has exactly similar wording as other documents (such as the Declaration of Helsinki). The key word in fact is "sole"; if society is seriously threatened, for example, by an epidemic, individual interests can be restricted, as expressed in Article 27. It has to be seen whether the right balance has been struck between universal human values and cultural difference<sup>12</sup> and what will be the usefulness of the Declaration in the diverse practices of bioethics.

## 7 Implications and Impact

Bioethical problems commonly arise because conflicts exist between several competing ethical principles. Sometimes it is not obvious which principle is to prevail. Accordingly, a careful balancing of principles is usually required. The Declaration states principles that may occasionally seem inconsistent. However, ethical decision-making in practice frequently requires rational argumentation and the weighing of the principles at stake. In order to advance decision-making, the principles are to be understood as complementary and interrelated (Art. 26).

It is significant that all 191 Member States of UNESCO were able to agree upon the relevant bioethical principles. The Declaration, although a non-binding legal instrument is therefore the first international document in bioethics adopted by all governments. Other very influential documents have been adopted by non-governmental organizations (e.g. the Declaration of Helsinki). However, generally, these do not create the same commitment on the part of governments. It is significant that the UNESCO Declaration has already been cited as relevant international text in the recent judgment of the European Court of Human Rights in the Case of *Evans v the United Kingdom*.<sup>13</sup> The Declaration is furthermore the beginning rather than the end of a process of internationalization of bioethics. Special attention therefore needs to be given to the application of the principles and the dissemination and the promotion of the Declaration. Member States that have not already done so will be encouraged to establish bioethics committees; to promote informed pluralistic public debate; to foster bioethics education and training; and to take appropriate legal measures to facilitate transnational research. International organizations such as UNESCO will continue to assist countries to develop an ethical infrastructure so that human beings everywhere can benefit from the advances of science and technology within a framework of respect for human rights and fundamental freedoms.

## Notes

<sup>1</sup> Full text: <http://portal.unesco.org/shs>

<sup>2</sup> Huxley 1946.

<sup>3</sup> Resolution 24, 2003.

<sup>4</sup> Report of the IBC 2003.

<sup>5</sup> Landman and Schuklenk, 2005: iii.

<sup>6</sup> Williams, 2005 5: 211.

<sup>7</sup> Benatar 2005, 5: 221.

<sup>8</sup> Macklin, 2005 5: 246.

<sup>9</sup> Landman and Schuklenk, 2005: vi.

<sup>10</sup> Faunce, 2005 31:173–178.

<sup>11</sup> Nys, 2006 13:5–8.

<sup>12</sup> Jing-Bao, 2005 5: 251–257.

<sup>13</sup> European Court of Human Rights 2006.

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## Annex: Universal Declaration on Bioethics and Human Rights – Principles

### *Article 3 – Human Dignity and Human Rights*

Human dignity, human rights and fundamental freedoms are to be fully respected.

The interests and welfare of the individual should have priority over the sole interest of science or society.

### *Article 4 – Benefit and Harm*

In applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients, research participants and other affected individuals should be maximized and any possible harm to such individuals should be minimized.

### *Article 5 – Autonomy and Individual Responsibility*

The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who

are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.

### ***Article 6 – Consent***

- a) Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.
- b) Scientific research should only be carried out with the prior, free, express and informed consent of the person concerned. The information should be adequate, provided in a comprehensible form and should include the modalities for withdrawal of consent. The consent may be withdrawn by the person concerned at any time and for any reason without any disadvantage or prejudice. Exceptions to this principle should be made only in accordance with ethical and legal standards adopted by States, consistent with the principles and provisions set out in this Declaration, in particular in Article 27, and international human rights law.
- c) In appropriate cases of research carried out on a group of persons or a community, additional agreement of the legal representatives of the group or community concerned may be sought. In no case should a collective community agreement or the consent of a community leader or other authority substitute for an individual's informed consent.

### ***Article 7 – Persons without the Capacity to Consent***

In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent:

- a) authorization for research and medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent;
- b) research should only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law, and if there is no research alternative of comparable effectiveness with research participants able to consent. Research which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and, if the research is expected to contribute to the health benefit of other persons in the same category, subject to the conditions prescribed by law and compatible with the protection

of the individual's human rights. Refusal of such persons to take part in research should be respected.

### ***Article 8 – Respect for Human Vulnerability and Personal Integrity***

In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

### ***Article 9 – Privacy and Confidentiality***

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law.

### ***Article 10 – Equality, Justice and Equity***

The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.

### ***Article 11 – Non-discrimination and Non-stigmatization***

No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.

### ***Article 12 – Respect for Cultural Diversity and Pluralism***

The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope.

### ***Article 13 – Solidarity and Cooperation***

Solidarity among human beings and international cooperation towards that end are to be encouraged.

### ***Article 14 – Social Responsibility and Health***

- a) The promotion of health and social development for their people is a central purpose of governments, that all sectors of society share.
- b) Taking into account that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition, progress in science and technology should advance:
  - (i) access to quality health care and essential medicines, including especially for the health of women and children, because health is essential to life itself and must be considered as a social and human good;
  - (ii) access to adequate nutrition and water;
  - (iii) improvement of living conditions and the environment;
  - (iv) elimination of the marginalization and the exclusion of persons on the basis of any grounds; and
  - (v) reduction of poverty and illiteracy.

### ***Article 15 – Sharing of Benefits***

- a) Benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, in particular with developing countries. In giving effect to this principle, benefits may take any of the following forms:
  - (i) special and sustainable assistance to, and acknowledgement of, the persons and groups that have taken part in the research;
  - (ii) access to quality health care;
  - (iii) provision of new diagnostic and therapeutic modalities or products stemming from research;
  - (iv) support for health services;
  - (v) access to scientific and technological knowledge;
  - (vi) capacity-building facilities for research purposes; and
  - (vii) other forms of benefit consistent with the principles set out in this Declaration.
- b) Benefits should not constitute improper inducements to participate in research.

### ***Article 16 – Protecting Future Generations***

The impact of life sciences on future generations, including on their genetic constitution, should be given due regard.

***Article 17 – Protection of the Environment, the Biosphere and Biodiversity***

Due regard is to be given to the interconnection between human beings and other forms of life, to the importance of appropriate access and utilization of biological and genetic resources, to the respect for traditional knowledge and to the role of human beings in the protection of the environment, the biosphere and biodiversity.

# Autonomy and Genetic Privacy

Juha Räikkä

The right to privacy and the right to autonomy or self-determination are interrelated in various ways, but they are still very different rights. In this paper I will discuss some of the relations and differences between those rights. The motivation behind this task is the idea that clarification of the right to privacy and the right to self-determination may be very important when we talk about the notion of genetic privacy and practical issues related to it.

## 1 The Right to Self-determination

What is meant by the right to autonomy or self-determination? When people say that a person is free they may mean that she determines herself, i.e. she makes decisions by herself that concern *only herself*, or more precisely, that concern others only in such a way that they cannot have any justified claim against the decision in *normal circumstances*. For example, when an adult is home alone and decides whether or not to watch TV, the decision does not normally concern others in such a way that they could have a justification for opposing that decision. On the other hand, when a person decides to punch someone in the face or to ignore the cries of someone in distress, these decisions normally do concern others in such a way that people have a justification for opposing them. Therefore, it is not purely an individual's own business to decide whether or not to punch someone.

The view that freedom is self-determination differs from the view that freedom is an opportunity to act in various ways. A person who makes her own decisions might nevertheless not have an opportunity to travel, to play tennis or to buy nice cars, for instance. And a person who has an opportunity to do many things does not necessarily make the decisions about *how* to act by herself. Nor should the view that freedom is self-determination be equated with the view that a person without unsatisfied needs is necessarily free, for a person who determines her own affairs

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J. Räikkä  
University of Turku, Finland  
e-mail: iraiikka@utu.fi

may still be very unsatisfied. On the other hand, a person who is satisfied might not be self-determining: someone else might have made the decisions resulting in her satisfaction. Freedom as personal self-determination is therefore an independent way of understanding freedom.

What exactly is meant by “personal self-determination”? Clearly, not everyone does determine herself. If a person is incompetent to make decisions and to act on the basis of her desires and beliefs, she certainly does not determine herself. If a person does not have any authentically formulated desires and beliefs of her own, then even if she is able to make decisions, she does not determine herself. Furthermore, even if a person has authentic desires and beliefs and is able to make decisions and to act on the basis of them, it does not necessarily follow that she determines herself. For if a person does not have power over the matters that determine whether she could act on the basis of her decisions, she does not determine herself. Thus it seems that at least the following three conditions should be met when a person genuinely determines her affairs: first, she should be competent; second, she should have authentic desires and beliefs; and third, she should have power to implement her desires.

A person can be said to be *competent* when she is able to make decisions and act on the basis of her desires and beliefs. To be competent a person must have certain general abilities which are needed in almost any situation where decisions are made. A person has *authentic*, self-selected desires and beliefs when her desires and beliefs are not formulated merely by indoctrination or extremely paternalistic education. When we ask whether a person is competent, we are interested first of all in *what* beliefs and desires she has and *how* she thinks, desires, and acts on the ground of the beliefs and desires that she happens to have. But when we ask whether a person has authentic desires and beliefs, we must inquire into the *roots* of her desires and beliefs. A person has *power* when she is not actively prevented from performing acts concerning only herself. Although a notion of “power” can be used in various senses; a person is certainly powerless (in a relevant sense) if there is an external constraint, say the police forces of a tyrannical government, that prevents or hinders such action. On the other hand, one could argue that a person has power only if, when necessary, she is sufficiently helped to act, i.e. when she is not passively prevented from acting.

Since personal self-determination is often equated with personal freedom, many people think that people *should* have an opportunity to determine themselves. That is why people commonly speak about a moral *right* to personal self-determination. The notion of a moral right to self-determination has a long history, and the concept has a variety of meanings. To choose between different interpretations of self-determination is to determine several things. First, the choice determines whether the right to self-determination belongs only to competent (authentic) persons or to incompetent (inauthentic) persons as well. Second, the choice determines whether the obligations toward competent (authentic) and incompetent (unauthentic) persons are similar. Finally, the choice determines what kind of obligations the right to self-determination implies: an obligation not to prevent certain actions, an obligation to help to carry out certain actions, an obligation to help to develop capacities to act, or some combination of the above.

A distinction could also be made between a *strong* right to self-determination and a *weak* right to self-determination. To choose between strong and weak self-determination is to determine whether the obligations the right implies are *prima facie* obligations or *all-things-considered* obligations. Neither the choice between the different interpretations of the right to self-determination nor the choice between a strong and a weak right to self-determination will determine the *content* of the right. To determine the content of the right to self-determination is to determine exactly what are the normal circumstances under which others could have a justified claim against one's decision.

A strong moral right to personal self-determination is a right with no exceptions. If a person has a strong right to self-determination, there is no situation in which that right could be overridden by a more important right. A strong right to self-determination demands that the right to self-determination should be respected *always* – whatever the circumstances are. Those who support a strong right to self-determination should be very careful when they define the *content* of the right. If a right has no exceptions and if the content of the right is such that a person is free to do all kinds of things on the grounds of her right, the results may be counter-intuitive. For example, it is not intuitively plausible that a moral right to personal self-determination should be respected even if that would mean that hundreds of people die.

A weak moral right to personal self-determination allows exceptions. If a person has a weak right to self-determination, there are cases in which it is justified to override the right to self-determination. Perhaps it is justified to override a person's right to self-determination if doing so helps to save another person's life. In any case, a weak right to self-determination gives us only a *prima facie* obligation to respect persons' right to self-determination. In a given situation we should always first consider the circumstances and only then decide whether the right to self-determination should be respected. Those who support a weak right to self-determination avoid counterintuitive results more easily than those who defend the strong right: when the results of respecting the right are counterintuitive, the right could always be overridden. However, defenders of a weak right to self-determination have a problem too. For if they say that the right to self-determination should not be respected always, an immediate question is *when* it should be respected.<sup>1</sup>

## 2 The Right to Privacy

What is meant by the right to privacy? The definition of privacy is contestable, but we can distinguish three different aspects of privacy: (1) the right to control personal information, (2) restricted access, and (3) the right to a correct reputation.

(1) *The right to control personal information aspect of privacy.* Most often the "right to privacy" refers to the right to control personal information, and the idea is that a person's right to privacy is violated when information concerning her personal affairs is collected or distributed without her voluntary permission. People refer to

the right to privacy when they do not want to give certain information to outsiders. When a patient tells details of her health condition to a doctor, the doctor has an obligation not to reveal these things to irrelevant agents. A patient controls information concerning herself when medical information is distributed only to the agents she has authorized. Her right to privacy is violated if information is revealed to outsiders. Of course, the doctor-patient relation is only one context in which people refer to the right to privacy. Enterprises have restrictions on customer registers. The employers are asked not to read employees' e-mails. Libraries are not supposed to have files that reveal what kinds of books a customer has read on the whole. Police officers are not supposed to reveal information regarding suspects. Biobanks or genetics databases should not reveal medical information to unauthorized persons.<sup>2</sup>

Suppose that Jack says to Helen that he will not be her friend anymore if she does not reveal for whom she voted in the previous presidential elections. If Helen tells for whom she voted, her right to privacy is violated, because she does not reveal this information voluntarily but because of Jack's threat. (Of course, there is a choice, but it is involuntary in the sense that had there not been the threat, she would not have chosen so.) Suppose, however, that Helen decides not to tell for whom she voted. In this case Helen's privacy is not violated and she manages to keep her personal information in her hands. Of course, one can still heavily criticize Jack, because he *did not respect* Helen's privacy, but *tried to violate* her right. Suppose, finally, that Helen decides to tell Jack for whom she voted in the previous presidential elections before Jack threatens her. Again, her privacy is certainly not violated, even if Jack now knows for whom she voted. Helen revealed her candidate voluntarily, and that is essential.

(2) *Restricted access aspect of privacy.* Gathering and distributing information of a person's personal affairs without permission is not the only way how her privacy may be violated. The right to privacy is also compromised if a person is (a) *observed* or (b) *disturbed* in certain, morally suspect, ways. Unauthorized watching may violate a person's privacy, even if the purpose of watching is not information gathering. Suppose a young man follows a woman's life in her home by using a pair of binoculars. He violates her privacy whether or not he has learned anything new about her. And he violates her privacy whether or not he sees her naked or in the toilet or anything like that. Suppose, however, that the woman gives permission for watching and even puts a web cam into her kitchen. In this case the young man does not violate her privacy, although we can say that the woman has considerably less privacy now than before her decision. Of course, these things need not happen in anyone's home, even if we speak about "domestic peace". One may violate a person's privacy for instance in a dressing room at work – by putting cameras there without letting anyone know that.

Watching and listening may violate the right to privacy, but often the violation constitutes *disturbance*. If somebody listens to your phone call, you may be unaware of it; but if somebody disturbs you, you certainly notice that. A person may be disturbed for instance by frequent phone calls at night, unwelcome intimate letters, offensive touching, or even noise. It is partly a subjective matter what counts as

disturbance. If I want somebody to call me at 3 A.M., it is not disturbance. The intentions of the caller are not an essential issue here: one may disturb you unintentionally – as people who have fallen in love with you sometimes do, or as older relatives often do. Perhaps these should count as violations of privacy which are excusable. Obviously, not all disturbing phone calls or letters are violations of privacy. A fireman who gets an alarm phone call at 4 A.M. is probably disturbed, but as he has made an agreement of these kinds of calls, issues of privacy are not relevant.

(3) *The right to a correct reputation aspect of privacy.* The third category of privacy violations consists of libels and identity thefts. Rumors or pictures may portray a person in a bad light, and here a person's privacy is violated again. They affect her reputation and consequently her identity in the eyes of others. Defamation violates one's privacy, and so do identity thefts, where a person acts as if she was someone else. Identity thefts are nowadays common because of increased shopping on the Internet. In a sense, the discussion of the reputation as an aspect of privacy started the modern debate on the right to privacy. In 1890 *Harvard Law Review* published Samuel D. Warren and Louis D. Brandeis' article "The Right to Privacy", in which they criticize Boston newspapers and wrote that "gossip is no longer the resource of the idle and of the vicious, but has become a trade, which is pursued with industry as well as effrontery".<sup>3</sup> That was the start of the academic discussion on privacy.

### 3 Connections and Differences

A typical confusion between the right to privacy and the right to self-determination can be found in US legislation, where a (legal and moral) right to abortion is protected by the (legal and moral) right to privacy. Although the issues of privacy are certainly related to abortion – many people would like to keep quiet about having had abortion – a person's right to decide whether she has an abortion or not must be based on her right to self-determination, not to privacy. "Decisional privacy" is not really a form of privacy. As Anita L. Allen points out in her 1988 book *Uneasy Access: Privacy for Women in a Free Society*,

free choice regarding whether or not to bear a child, choice free of governmentally imposed constraints, is the "privacy" (...) often emphasized in connection with reproductive rights. Strictly speaking, (...) free choice is not a form of privacy. Solitude anonymity, and information disclosure are aptly described as forms of privacy, because they designate respects in which persons, their mental states, and information about them are to some extent inaccessible to others. Free choice is not a form of privacy, even though it relates to one's capacity to control one's privacy, one's private life and one's own body.<sup>4</sup>

It is clear that an act *can* violate both the right to privacy and the right to self-determination, or neither of them. If someone attacks your home in the evening and prevents you from watching TV, she violates both rights. On the basis of the right to privacy (and many other rights), you should be protected from attacks on your home; on the basis of the right to self-determination, you should be free to choose

whether you watch TV or not. But not all violations of privacy are violations of self-determination too, and not all violations of self-determination are violations of privacy. Swedish philosophers Anders J. Persson and Sven Ove Hansson seem to be right when they distinguish “sphere of privacy” (protected by the right to privacy) and “private sphere” (protected by the right to self-determination):

This “sphere of privacy” is analogous to, but not identical with, the more well-known “private sphere” that is central to liberal political thought since John Stuart Mill. The private sphere is a zone in which the individual should be allowed to make her own decisions, whereas the sphere of privacy is a zone in which legitimate concerns may arise about others’ access to and information about her. These two spheres may overlap in many situations, but neither of them seems to include the other. To see this, first consider a person who is treated for a venereal disease. Since this disease is a danger to others, the decision to treat it does not belong to the private sphere. (...) Nevertheless, the nature of his/her disease is obviously a matter in which his/her privacy is concerned. Next, consider a person’s choice of the outdoor clothes that (s)he wears when (s)he comes to work. This choice certainly belongs to the private sphere, but claims of privacy are hardly applicable to it.<sup>5</sup>

In ordinary language people do not make a big difference between the right to privacy and the right to self-determination. Expressions such as “it is my business” may refer to either of these rights. Suppose a doctor who is a chain smoker defends herself by saying that it is her business whether she smokes or not. She may mean that on the basis of her right to self-determination she is free to decide whether she smokes or not. Suppose, on the hand, that surprisingly a philosophy professor leaves her chair, and when her colleagues ask why she did so, she answers that it is her business. She means that it is her private matter and on the basis of her right to privacy she need not tell the reasons to anyone.

Now, it is often argued that the value of privacy is based on the value of self-determination. We value the right to self-determination, because it gives us freedom to do this and that. But without the right to privacy, we will not *use* the right to self-determination, or so the argument goes. For instance, on the basis of the right to self-determination we are free to sing when taking a morning shower, but if there were no privacy (and there were for instance microphones in the bathroom), probably we would not sing. Blanca R. Ruiz puts forward this argument in her article “The Right to Privacy”, published in *Ratio Juris* in 1998:

What privacy is wanted for is one’s autonomy to take intimate decision or, more broadly, one’s autonomy to take and carry out decisions in private: If individuals want to keep control over their areas of seclusion and secrecy it is in order that they can exercise their autonomy free from the intrusive eyes of both the public power and society. What privacy is wanted for is, in other words, one’s freedom to act in private.<sup>6</sup>

A similar point is defended by Seumas Miller who writes that “a measure of privacy is necessary simply in order for a person to pursue his or her projects, whatever those projects might be”.<sup>7</sup>

This argument is reasonable, but it must be kept in mind that unauthorized watching, for instance, may affect my decisions (say, to dance alone in the kitchen) only if I know or at least suspect that someone is watching me. And certainly

unauthorized watching is morally problematic in these cases too, i.e. in cases when it does not have any effect on my willingness to use my right to self-determination. There is another important point to make here too. Not all violations of privacy affect a person's willingness to use her right to self-determination. Suppose someone publishes a libel that Jack and Helen, both married but not to each other, have an affair. This violates their right to privacy, but arguably it does not have any effect on their willingness, say, to sing in the shower or dance alone in the kitchen.

## 4 Applications: The Notion of Genetic Privacy

There has recently been much discussion about *genetic privacy*. A short review to the discussion suggests that the notion of genetic privacy has a variety of meanings. In this final part of my presentation, I will briefly analyse how these meanings relate to the characterizations made above.

In his sophisticated and well written dissertation *Genetic Information, Values and Rights* (2005) Niklas Juth defines the "received opinion" and "common understanding" of genetic privacy as follows:

genetic privacy is protected when the person herself has full control over her genetic information, without the risk of adverse consequences to herself, whatever she chooses to do with it (at least as long as she does not use it to harm others). If she can be excluded from insurance because of negligence to disclose genetic information to insurance companies, her genetic privacy is not being fully respected, according to this understanding of privacy.<sup>8</sup>

Whatever the merits of the "common understanding" of genetic privacy are, it is important to note that it is not in line with the general analysis of the right to privacy given above. Why not say that an insurance company violates the privacy rights of those customers who reveal personal information under threat, but that it only *tries* to violate the privacy rights of other customers and hence *does not respect* their right to privacy? This kind of analysis would not make the insurance company any less morally responsible. But it would save us from the counterintuitive consequence that an insurance company may violate a customer's right to control personal information even if the customer is still controlling it.

Another kind of interpretation of "genetic privacy" can be found from Karen Lebacqz's article on "Genetic Privacy: No Deal for the Poor" (1998). She writes as follows:

First, "privacy" means that I have the right not to know my genetic status if I choose not to. (...) Second, "privacy" means that if I do know my genetic status, I do not need to share that information with others. (...) A third "right" is also generally encompassed under the presumed right of genetic privacy: the right to use information to make decisions based on one's own values and without coercion from others. (...) Genetic privacy would therefore encompass three notions: a right not to know one's genetic status if one so chose, a right not to tell others or to have others know, and a right to use genetic information to make decisions within the framework of one's values.<sup>9</sup>

This kind of understanding of genetic privacy is, again, in conflict with the more general analysis of the right to privacy, and it comes close to the right to self-determination. A “right not to tell others or to have others know” is clearly a privacy right and is part of the aspect of privacy that constitutes the right to control personal information. But “a right to use genetic information to make decisions within the framework of one’s values” seems to be related to the right to self-determination rather than the right to privacy.

“A right not to know one’s genetic status if one so [chooses]” is an interesting case. Suppose a person decides to take genetic tests and goes to a private business enterprise in order to get them. However, when the results are ready, she decides that, actually, she does not want to hear about them. But a very polite business man tells them to her anyway and says that she does not need to worry: “Everything is perfectly okay!” What went wrong? We may say that her right to privacy is violated, because on the basis of that right she is supposed to have a right to control who will get information concerning her personal affairs, and here this kind of information is distributed to an unauthorized agent, namely, to herself. But somehow this sounds highly artificial: the idea is that those “unauthorized” agents should be other persons. A more plausible analysis of the case is that her right to self-determination is violated. On the basis of that right, she has a right to decide whether she reads a newspaper, watches TV news or – hears about the results of her genetic tests. Of course, the relation between the right to self-determination and the right not to know is much more complicated, but it is plausible to say that these rights are related.

In many other contributions “genetic privacy” has been defined in different ways. Mary R. Anderlik and Mark A. Rothstein argue in their 2001 article “Privacy and Confidentiality of Genetic Information” that privacy “is a broad concept that subsumes” many categories, one of them being a right to escape “third-party interference with personal choices, especially in intimate spheres”.<sup>10</sup> Obviously, the issue here seems to be the right to self-determination rather than the right to privacy. Ludvig Beckman writes in his 2005 paper “Democracy and Genetic Privacy” that “genetic privacy could be modeled on the basis of an account of a right to bodily integrity”.<sup>11</sup> This, again, is a new interpretation of the concept.<sup>12</sup>

Now, what should be concluded from these different ways of using the notion of genetic privacy? One possibility is that we simply accept the diversity and the fact that these interpretations are not in line with the more general understanding of the right to privacy. Perhaps Pamela Sankar is right when she writes that “there is no single correct definition of genetic privacy”.<sup>13</sup> Another possibility is that we revise the general understanding so that it fits better with current ways of using “genetic privacy”. After all, the “general understanding” of privacy presented above is just one interpretation of the right to privacy. The final possibility is that the notion of genetic privacy is redefined so that it is in line with the more general right to privacy. I sympathize with the last proposal, as it will make discussion far easier and clearer in the field.<sup>14</sup> This solution would also have important practical consequences, as the genetic privacy claims would have different meaning than they now have.

## Notes

<sup>1</sup> For a discussion, see e.g. John Christman, “Constructing the Inner Citadel: Recent Work on the Concept of Autonomy”, *Ethics* 99 (1988), 110–111; Gerald Dworkin, “The Concept of Autonomy” in R. Haller (Ed.) *Science and Ethics* (Rodopi, Amsterdam 1981), 203–213; Susan Easton, “Autonomy and the Free Speech Principle”, *Journal of Applied Philosophy* 12 (1995), 27–39; Joel Feinberg, “Autonomy” in his *Harm to Self* (Oxford University Press, New York, 1986); John Harris, *The Value of Life* (Routledge, London 1985), 209; Richard Lindley, *Autonomy* (Macmillan, Hong Kong 1986), 63–69; Wesley Hohfeld, *Fundamental Legal Conceptions as Applied in Juridical Reasoning* (Yale University Press, London 1964); Douglas Husak, *Drugs and Rights* (Cambridge University Press, Cambridge 1992), 82; Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press, Cambridge 2002); David Ost, “The ‘Right’ Not to Know”, *The Journal of Medicine and Philosophy* 9 (1984), 301–312.

<sup>2</sup> For discussion, see e.g. Vilhjálmur Árnason, “Coding and Consent”, *Bioethics* 18 (2004), 27–49.

<sup>3</sup> Samuel D. Warren and Louis D. Brandeis, “The Right to Privacy”, *Harvard Law Review* 4 (1890), 193–220.

<sup>4</sup> Anita L. Allen, *Uneasy Access: Privacy for Women in a Free Society* (Rowman & Littlefield, Totowa 1988), 97.

<sup>5</sup> Anders J. Persson and Sven Ove Hansson, “Privacy at Work: Ethical Criteria”, *Journal of Business Ethics* 42 (2003), 59–70, esp. 61.

<sup>6</sup> Blanca R. Ruiz, “The Right to Privacy: A Discourse-Theoretical Approach”, *Ratio Juris* 11 (1998), 155–167, esp. 158.

<sup>7</sup> Seumas Miller, “Privacy, Data Bases, and Computers”, *Journal of Information Ethics*, Spring (1998), 42–48, esp. 44.

<sup>8</sup> Niklas Juth, *Genetic Information, Values and Rights* (Kompendiet, Göteborg 2005), 399.

<sup>9</sup> Karen Lebacqz, “Genetic Privacy: No Deal for the Poor” *Genetics: Issues of Social Justice*, (1998), pp. 240–241.

<sup>10</sup> Mary R. Anderlik and Mark A. Rothstein, “Privacy and Confidentiality of Genetic Information”, *Annual Review of Genomics and Human Genetics* 2 (2001), 401–433.

<sup>11</sup> Ludwig Beckman, “Democracy and Genetic Privacy: The Value of Bodily Integrity”, *Medicine, Health Care and Philosophy* 8 (2005), 97–103.

<sup>12</sup> For further characterizations of genetic privacy, see e.g. Barbara Bowles Biesecker, “Privacy in Genetic Councelling” in M.A. Rothstein (Ed.) *Genetic Secrets* (Yale UP, 1997); D.L. Wiesenthal and N.I. Wiener, “Privacy and Human Genome Project”, *Ethics & Behavior* 6 (1996); Lawrence O. Gostin, “Personal Privacy in the Health Care System”, *Kennedy Institute of Ethics Journal* 7 (1997); W.C. Zimmerli, “Who Has the Right to Know the Genetic Constitution of a Particular Person?” in *Human Genetic Information* (Ciba Foundation, 1990).

<sup>13</sup> Pamela Sankar, “Genetic Privacy”, *Annual Review of Medicine* 54 (2003), 393–407, esp. 393.

<sup>14</sup> I do not intend to claim that there are no disagreements what the right to privacy in general means. Obviously, the notion of privacy is very contestable. The point is that it is still less contestable than the notion of genetic privacy.

# Values, Rights and GMO: Against Radicalism

Niklas Juth

## 1 Introduction

Despite the ambitious title, the scope of this paper is rather restricted. I will exclusively address the question of whether or not allowing the commercial marketing of GMO, that is, the commercial production (e.g. planting or farming), selling, and purchasing of products that consist of or contain genetically modified organisms is justified.<sup>1</sup> Consequently, some of the most debated ethical questions regarding GMO will not be addressed.<sup>2</sup>

For instance, I will not discuss the question of what kinds of GMO-research should be performed or allowed, if any. Although the border between basic research and its application is rather vague, I will assume that the border between allowing basic research and allowing commercial marketing is sufficiently clear, at least for regulation purposes. These issues should, however, be distinguished, partly because allowing research on GMO is less controversial than allowing the marketing of GMO:<sup>3</sup> those who oppose the former always oppose the latter, while some of those who oppose the latter do not oppose the former. This last position is quite natural if one opposes the marketing of GMOs due to present uncertainty regarding possible consequences for the environment and health. Research may reduce such uncertainty, and so may be welcomed on these grounds. So even if one opposes allowing marketing of GMO one may, or may not, oppose GMO-research.

Furthermore, I will not discuss questions regarding GMO and patenting. Although some of these questions are clearly about rights, they cannot be given the space they deserve within this paper.<sup>4</sup> Neither will I discuss the precise details of how GMO should be regulated. I will thus not say anything about what standards producers of GMO should meet in order to be allowed to market their products, for instance, what risks they have to demonstrate, the extent to which they should be liable for damage caused by their products, if they should be only allowed to grow GM crops in plant houses etc. Moreover, the focus will be upon genetically modified

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N. Juth

Doctor of Philosophy and Senior Lecturer in Medical Ethics at Karolinska Institutet, Sweden  
e-mail: niklas.juth@ki.se

microorganisms and plants and not animals, since animals come with a host of moral problems of their own.<sup>5</sup> However, some of the argument is also relevant for issues related to genetically modified animals.<sup>6</sup>

Even though my scope is somewhat limited, the position I defend is perhaps not so controversial, at least not in my own mind. I will argue that *being in favour of or opposing* the allowing of commercial marketing of GMO *in general* are both implausible positions. Rather, the balance of reasons is likely to vary from case to case. The simple reason for this is that there are different values and disvalues at stake depending on which genetically modified organism we are dealing with, and under what circumstances. Thus, determining whether or not to allow marketing of GMO should probably take place on a case to case basis, rather than by creating blanket regulations.

Even though I have defined the issue somewhat narrowly and my standpoint on the issue is somewhat uncontroversial, there are two main reasons for posing the argument to follow. First, the radical positions, that is, either the position that all commercial marketing of GMO should be allowed or that all such marketing should be banned, have in fact been adopted. Not least the prohibitionist stand has gained considerable support in the political arena.<sup>7</sup> Indeed, the public debate on GMO sometimes gives the impression that one's only choice is between one of the two radical positions. However, although occupying middle ground is often much less exciting, it is sometimes the most reasonable position. I will argue that this is so regarding the issue of allowing the commercial marketing of GMO.

Second, I believe the main argument has some philosophical interest in its own right. I will argue that there are no absolute rights or lexically prior intrinsic values. At least, I will suggest why claims to the contrary are hard to defend, at least regarding values and rights relevant to the discussion of GMO. Moreover, I will determine what one has to presuppose in order to be a radical in the area of GMO. In so doing, I will map some possible value foundations for being in favour of or opposing GMO, which I believe can be useful means of clarifying different nodes of disagreements which are sometimes conflated.

Although the middle ground is seldom an exciting position, it is often an uneasy position to occupy when radical antagonists on both sides exist. On the one side, there is the position that the commercial marketing of GMO should always be permitted, in the sense that there should be no regulative interference in the marketing of GMO. As we will see, the most basic and yet straightforward rationale for this position is by reference to the radical liberal theory of rights called libertarianism. Thus, this position will henceforth be called *Radical Libertarianism*. On the other side, there is the position that the commercial marketing of GMO should never be permitted. As we will see, the most basic and yet straightforward rationale for this position is by reference to some values that the marketing of GMO would or could threaten, e.g. health, ecological stability or diversity, sustainable development, and so on. This position will henceforth be called *Radical Prohibitionism*. I will argue that both Radical Prohibitionism and Radical Libertarianism are implausible positions.

Already at this point, it is important to emphasise that no one has ever actually and explicitly developed the radical positions I will present in the following,

at least not to my knowledge. Thus, and in that sense, these positions are straw men. However, the kinds of arguments that I present are very common.<sup>8</sup> And many present their position *as if* they occupy one of the radical positions, although their rationale is sometimes unclear. So the point of reconstructing these arguments is to demonstrate what one has to presuppose in order to be a radical regarding GMO to the degree that some *seem* to be. Moreover, the more one approaches the radical positions, the more problems one faces with an underlying rationale that is implausible.

## 1.1 Democracy

Sometimes, democracy is thought of as merely a way of making decisions, for instance in accordance with the vote of the majority of competent adults in a territory or by the vote of a properly elected representative body.<sup>9</sup> More often, however, democracy is thought of as an ideal intimately connected to certain values and rights.<sup>10</sup> Holders of different ideals of democracy have different opinions about the proper place of democracy within societies: what decisions should be democratic, in what way, and to what extent. Moreover, some ideals state that democratic decisions should meet certain standards in order to be “good” from the democratic point of view.<sup>11</sup> For instance, so-called deliberative democratic ideals emphasise the formation of opinions preceding public decisions: such decisions should be preceded by a free, equal and rational discussion where everyone involved has their say. Otherwise the decisions can be criticised from the democratic point of view, even if they are supported by the majority.<sup>12</sup>

However, any ideal of democracy must be founded on some idea about the *point* or, if you will, *value* of democracy: why is democracy (in the way advocated by the ideal in question) a good thing? Answering this question is necessary in order to evaluate the ideals of democracy. Of course, there are different answers. One relates to autonomy: democracy is good because it permits persons to be a part in determining decisions that affect what happens to them.<sup>13</sup> Another relates to equality: democracy is good because it expresses an equal respect for everyone (one man, one vote).<sup>14</sup> Yet another relates to authority: it may be held that we have a moral reason to follow decisions that we have had a say in. A similar answer relates to legitimacy: we tend to respect decisions that we at least have a possibility to affect.<sup>15</sup> Since not everyone’s wishes can be satisfied, another argument is that it is better to satisfy the majority rather than the minority.<sup>16</sup> There is also the traditional answer of democracy as a way of reaching a common good.<sup>17</sup>

Different democratic values support different particular ideals. If one important point of democracy is legitimacy, there is an argument in favour of the deliberative ideal: equal and free participation in the discussion preceding decisions is likely to promote respect for these decisions once made. However, the will-formation as such becomes less important if satisfying the majority’s wishes is considered to be more important.

Regardless of why one values democracy, I think it would be most unwise to defend democracy on the basis that all democratic decisions are morally justified or reasonable simply because they are democratic. Rather, one should carefully distinguish between the question of *who* should make certain decisions and the question of *what* they ought to decide. Similarly, *how* decisions should be made regarding a certain issue and *what* speaks in favour of making a certain decision rather than another are two different questions. Another related difference is the one between what most people think about a certain issue and what reasons there are to think one way or the other regarding this. Regardless of what ideal of democracy one deems plausible in the end, I think one should concede that one important point of democracy is that democracy recognizes and respects disagreements and allows practical issues in the face of such disagreements to be solved. This is why discussions before decisions are meaningful and important from a democratic point of view – they allow for the formation of a well-founded opinion when there is initial disagreement on an important issue. Even if some disagreement remains after the discussion, hopefully the issue has been illuminated from various points of views making the final decision more reasonable.

This paper is about what standpoint is most reasonable regarding one specific issue: the question whether or not allowing the commercial marketing of GMO is justified. I am thereby entering a discussion on a particular question regarding GMO that should precede any democratic decision on this question. I will also take a stand on what I think is the most plausible position regarding this question or, at least, on what positions that are implausible. Thus, I will not attend to one common argument against GMO: that people generally oppose the marketing of GMO-products.<sup>18</sup> Even if this argument perhaps should be given some weight in the debate on whether or not the marketing of GMO should be allowed (according to some democratic ideal), it is irrelevant to the question of the *acceptability* or *reasonableness* of allowing GMO, which is the question in this context.

## 2 Rights

Both the radical positions can be described in terms of rights. Accordingly, Radical Prohibitionism can be described as the position that there should be no right to produce, sell, and purchase GMO-products, at least not by private enterprises for commercial purposes. Analogously, Radical Libertarianism can be described as the position that the right to produce, sell, and purchase GMO-products should be recognized without exceptions and limitations.

However, rights-talk is far from unambiguous. There are different kinds of rights, and rights can typically be divided into various elements.<sup>19</sup> The rights we are dealing with in this context are *negative* and *legal*. Negative rights can be characterised in terms of the moral reasons for others to act or abstain from acting towards the right-holder in various ways: such rights corresponding to others<sup>20</sup> having a reason<sup>21</sup> not to deprive the right-holder of, or not to prevent her from acquiring, that to which she

has a right. Negative rights are therefore sometimes described as the right not to be prevented from doing or having something, or the right to *non-interference*.

Negative rights are often distinguished from positive rights, i.e., rights that correspond to at least one other person having a reason to provide the right-holder with, or to help her maintain hold of, that to which she has a right. Positive rights to GMO are rarely proposed in discussions on GMO, although there are exceptions.<sup>22</sup> Since we are dealing with the question of whether or not commercial actors should be allowed to market GMO or if they should be in any way prevented from doing so, positive rights are irrelevant in this context.<sup>23</sup>

Since we are here dealing with the question of how the commercial marketing of GMO should be regulated, the rights under discussion are legal rights, i.e., rights that are recognized and enforced by some legislating societal institution. It is tempting to think that negative rights should always be enforced, since such rights imply that we all have strong reasons not to prevent someone from doing something. However, even if preventing someone from doing something would be straightforwardly wrong, it does not follow that societal institutions should in any way enforce sanctions to ensure that the prevention is prevented or punished. Thus recognising certain rights as legal rights is not self-evident.

### 3 Radical Libertarianism

Although Radical Libertarianism regarding the regulation of the commercial marketing of GMO is seldom explicitly defended, it is often considered as the default position in liberal theory and liberal societies. Those who defend restrictions on a free market are often presupposed to have the burden of proof. However, many commercial goods and services are the objects of various regulations on various grounds, or instance, transactions of most goods and services are taxed, food and pharmaceuticals are subject to various governmental quality controls, rules of consumer information and so on.

Let us recall the radicalism of Radical Libertarianism. According to this position, there should be *no* restrictions and limitations on the right to produce, sell, and purchase GMO-products *under any circumstances*. This requires a *principled* defence of such rights. I will argue that the only principled basis for the Radical Libertarian position is libertarianism. Since libertarianism ought to be rejected, Radical Libertarianism regarding the regulation of the commercial marketing of GMO ought to be rejected as well.

First, let us see why libertarianism in general would support Radical Libertarianism regarding GMO. Libertarian theories are united by backing up a strong kind of free market system without taxation and (stricter) regulation. My criticism will partly extend to all these libertarian theories, but I will concentrate most of my criticism on Nozick's theory.<sup>24</sup> The basic assumption of Nozick's theory is that we have certain absolute negative rights, foremost those relating to our body and acquired property. By virtue of this, no one may prevent the individual from using

her body, psychological capacities and justly acquired property in the way she sees fit, as long as the individual does not violate the rights of anyone else: I may destroy my justly acquired car if so wish, but not by deliberately crashing it into your porch. If all property is justly acquired, every voluntary transaction that does not violate anyone's rights will result in a just distribution, regardless of the pattern of distribution. "A distribution is just if it arises from another just distribution by legitimate means"<sup>25</sup> is Nozick's concise statement of this idea.

According to libertarianism, everyone is free to choose the terms she herself wants when engaging in a transaction with property to which she is entitled, just as she is free to accept or reject the terms of the other party of the transaction. Thus, the moral core of libertarianism is that normal adult persons whose capacity and competence to make decisions is not significantly diminished should be allowed to (i.e. should not be prevented from) consent to whatever arrangements they themselves want and act accordingly, at least as long as they do not violate the rights of others.

Consequently, when applied to the question of GMO, the reasoning that takes us from general libertarianism to Radical Libertarianism may be adumbrated as follows. Voluntary, i.e. mutually consented, transactions on the market should not be prevented. For instance, P may not legitimately be interfered with if P voluntarily establishes a contract that gives P a genetically modified product in exchange for economic compensation and another person (or a group of voluntarily cooperating people in a company) may not legitimately be interfered with if they offer P this product, given the terms of the contract she and they voluntarily consent to. To interfere with P by force or threat of force (or other sanctions that are not the result of normal market competition) is to violate P's right to engage in voluntary transactions. This is wrong, according to libertarianism. Thus, the state should allow the buying and selling of GMO-products, and the marketing of such products. Furthermore, given libertarian premises, it seems illegitimate for the state to limit this right to establish contracts, e.g. by demanding that the contracts have a certain content (for instance, by requiring that the content of GMO in a food product should be specified above the level voluntarily agreed by the parties of the transaction).

If one accepts the above line of reasoning, it seems as though one has to accept that it is wrong to prevent people from producing, selling, and buying genetically modified products, since it is generally wrong of the state to prevent voluntary transactions as long as other libertarian rights to life and property are not violated. So libertarian grounds seem to support legal negative rights to the commercial marketing of GMO in the way advocated by Radical Libertarianism.<sup>26</sup>

According to libertarianism, rights are absolute: it is *always* wrong to violate them. That is, there are no ethical considerations of any kind that can override the right in question.<sup>27</sup> Moreover, according to libertarianism, rights exclude the field of socially enforced rights – legislation should be exclusively concerned with the sanctioning of individual's rights.<sup>28</sup> Moreover, any legitimate state should enforce rights. This means that one can infer the presence of an *enforcement privilege* from the presence of a negative right in libertarianism. An enforcement privilege is the right to react against anyone who violates some negative right, e.g. by preventing the violation or by punishing or demanding compensation for already

performed violations. According to libertarianism, the state's obligation, indeed, the state's *only* legitimate obligation is to effectuate enforcement privileges. This means that one can infer legal rights from moral rights within the framework of libertarianism.<sup>29</sup>

These two characteristic features of libertarianism – that rights are absolute and that they always should be implemented as legal rights – explain why libertarianism is the only theory that can provide the required principled defence of Radical Libertarianism regarding GMO. Libertarianism is a *theory of rights*. Theories of rights are theories that acknowledge rights on the basic level. They hold that if an action violates a right this, in itself, is a reason to abstain from performing the action in question. To be sure, there are theories of rights other than libertarianism.<sup>30</sup> However, other theories of rights hold that there are other reasons for regulation than rights.<sup>31</sup> They are thus *moderate* theories of rights. Moreover, moderate theories hold that rights are not necessarily absolute. On the contrary, they hold most or all rights to be *prima facie*, i.e., it is possible to override a right if sufficiently strong reasons for doing so exist. So, in order to argue that some regulation should be implemented, establishing that this regulation would protect some right is insufficient. One also has to establish that there are no other ethical considerations that override the right in question. Furthermore, moderate theories of rights are open to societal regulations that do not perfectly mirror the moral rights recognized by such a theory. As already noted, it is not self-evident that societal institutions should legally enforce moral rights.

Due to all these features of moderate theories of rights, one cannot infer any particular regulation regarding GMO from these theories. Even if most moderate theories of rights perhaps would concur with the liberal default position that proposals of infringements of market transactions bear the burden of proof, they would be open to the possibility that there are such “proofs” or reasons weighty enough to regulate against the commercial marketing of GMO. This would involve weighing different reasons, where reasons in terms of rights are one of many types of relevant reasons in favour of or opposing certain regulations. Thus, the Radical Libertarian position that there should be *no* restrictions and limitations on the right to produce, sell, and purchase GMO-products *under any circumstances* cannot gain support unless there never are any reasons against such restrictions and limitations. Since, as we will see, there are such reasons, Radical Libertarianism's principled opposition to regulations of GMO cannot gain support from moderate theories of rights.

Of course, similar lines of reasoning are valid for any moral theory that does not defend absolute rights, but recognizes other moral reasons. Take, for instance, consequentialist theories. Such theories deny that there are *basic* rights, i.e., that there is a moral reason to respect certain rights, regardless of the consequences of doing so. However, consequentialists often defend *legal* rights on the basis that a particular institutional setting that involves the recognition of some rights are conducive to general welfare. Rights defended in this way are not moral rights, but legal rights which we have moral reasons to uphold. According to these consequentialists, it is an open question whether or not the commercial marketing of GMO should

be regulated or not depending, naturally, on the consequences of such regulations. More specifically, what regulation should be implemented according to some consequentialist theory would depend on what values the consequentialist theory in question would accept, how much relative weight these values should be assigned and the sort and magnitude of values and disvalues various alternative forms of regulation would realize. We will return to the question of which values are at stake regarding GMO and how they may be compared.

Since libertarianism, then, is the only theory that would ensure a successful defence of Radical Libertarianism regarding GMO, the plausibility of the latter position depends on the plausibility of the former. And libertarianism is a deeply implausible theory. Not only has libertarianism implausible normative consequences,<sup>32</sup> it is also an ideal that is practically impossible to realize because of the impossibility of determining which belongings are in fact justly acquired property.<sup>33</sup> Moreover, libertarianism is internally incoherent, since its defence of absolute rights to property does not follow from its moral premise of self-ownership.<sup>34</sup> All these points have been convincingly argued elsewhere, and there is no need to repeat them here. Instead, I shall focus on an additional argument against libertarianism that is of special relevance for the argument to follow.

One of the major flaws of libertarianism is due to its claim that legislation should not be concerned with *anything* but the sanctioning of individual's rights. This means that no other reasons for regulation are relevant. This is not to say that libertarianism denies that there are other normatively relevant considerations than respecting rights. According to Nozick there certainly are.<sup>35</sup> However, these considerations should never form the basis of politics, according to libertarianism.<sup>36</sup> This is not plausible at all. Firstly, it is not clear why all other morally relevant considerations become irrelevant in the area of legislation: why should all normative considerations besides respecting libertarian rights to life and property make a halt in this area? Second, it is not reasonable to hold that no amount of any value can ever override libertarian rights. Consider the radicalism of libertarianism: no considerations of human and animal welfare, autonomy, environmental values, equality of opportunity or what ever you take to be of importance can ever justify any regulation according to libertarianism. Thus, regulation, e.g. taxation, to remedy widespread poverty, massive starvation, ecological catastrophe, and gross inequalities would be illegitimate. Of course, libertarians deny that their proposed system would ever lead to such maladies. But if it would, reference to these other values in favour of regulation would be *irrelevant* according to libertarianism. If this is not implausible, I do not know what is.

## 4 Values

If Radical Libertarianism is founded upon rights, Radical Prohibitionism, i.e. the position that the commercial marketing of GMO should never be permitted, is founded upon values (although the position can be described in terms of rights).<sup>37</sup>

So in order to understand Radical Prohibitionism, one has to examine which values are at stake in discussions about GMO in greater depth.

Sometimes, the potential benefits or values that the production and marketing of GMO-products result in are emphasised. For instance, *environmental* benefits are sometimes pointed out. For instance, GMO-crops can reduce the use of pesticide and fertilizers in agriculture. According to some, this has already happened,<sup>38</sup> although the evidence for such claims has been contested.<sup>39</sup> Moreover, there are probably some *health-related* benefits that can be gained by the production and subsequent use of GMO-products, for instance by the consumption of rice enriched with vitamins and iron or rape with healthier combinations of fats. Other types of health related products are the various forms of genetically modified organisms used as pharmaceuticals, for instance insulin, vaccines, antibodies, and growth hormones.<sup>40</sup> Of course, many GMO-products may have advantages both in terms of the environment and health. For instance, microbes designed to assist the detoxification of contaminated water or fungal strains designed to degrade soil pollutants such as DDT and PCB can contribute both to protecting sensitive ecosystems and the health of creatures living in and from these ecosystems.<sup>41</sup> Similarly, the reduced use of pesticides may have benefits both in terms of environment and health. Furthermore, there are potential economic benefits which would arise if the marketing of GMO were allowed. Often, the gains in terms of resources for those who are worst off are brought to stand claims that world starvation can be alleviated to some extent by the use of GMO-products in agriculture have been made, although they have also been contested.<sup>42</sup>

Other critics emphasise the (potential) disvalues of GMO-products. To a large extent, these disvalues are similar to the benefits, i.e. environmental and health-related ones. For instance, using some GMO-products in agriculture may increase the need for herbicide when wild counterparts become more tolerant due to cross-pollination.<sup>43</sup> One of the most commonly stated worries related to GMO-crops is that cross-pollination may even lead to the extinction of wild counterparts. This relates to worries about monocultures, which may be deemed undesirable both because they reduce ecological values, such as biological diversity, or simply because they are plain ugly.<sup>44</sup> Some GMO-products may pose risks to both the environment and health. For instance, the potential transfer of antibiotic resistance genes from some GMO in agriculture to bacteria has given rise to concerns about reduced possibilities to treat infectious diseases.<sup>45</sup>

Of course, the actual or possible values and disvalues illustrated in these examples are of different kinds and may have different foundations. For one thing, economic benefits are obviously *instrumentally* valuable,<sup>46</sup> that is, they inherit their value from something else (for instance by giving more people the resources they need to live good lives). In opposition, health and some environmental values, such as biological diversity or ecological stability, may be thought of as *intrinsically* valuable, that is, of value in themselves.<sup>47</sup> Any instrumental value must ultimately inherit its value from some intrinsic value in order to be a value at all.

What does it mean to say that something has intrinsic value? According to the standard view, X being intrinsically valuable is closely related to anyone having a

*pro tanto* reason to promote X for its own sake.<sup>48</sup> A reason is *pro tanto* if, and only if, it always has “weight” or “force” (even though it may be overridden by other weightier reasons). So, if for example health is an intrinsic value, there is always a reason to promote it. Of course, there are different views on the relationship between having a *pro tanto* reason to promote X and X being intrinsically valuable.<sup>49</sup> However, they agree that there is a necessary connection between X being an intrinsic value and anyone having a *pro tanto* reason for promoting X. This means that talk about values can be reformulated into talk about reasons.

The most important explanation for the consensus on the necessary relation between intrinsic values and reasons is the intuitively plausible idea that there is a strong connection between values and norms. To deny this connection seems utterly strange, almost unintelligible: what would it mean to say that something is intrinsically valuable, that is, valuable in itself, if this does not at least imply that there is at least some reason, albeit possibly one which can be overridden, to promote the thing in question?<sup>50</sup>

It is no doubt highly controversial if the values mentioned above, i.e. primarily health and environmental values, really are examples of intrinsic values. For instance, health is sometimes thought of as merely being a means to well-being. On other occasions, health is considered to be an intrinsic value,<sup>51</sup> a position that is especially tempting if health is analysed partly in terms of well-being (the proper analysis of health also being a matter of controversy<sup>52</sup>), which is the least contested candidate for an intrinsic value.<sup>53</sup> I will not take a stand on the question of whether or not health is an intrinsic value, but only say that it is one of the candidates for being such a value.<sup>54</sup>

In discussions of environmental values, the issues become even more complex than when health is discussed. This is partly because the foundation or basis of such values is contested. On the one hand, there is the position that environmental values are merely instrumental values. According to this position, there is nothing intrinsically valuable about entities such as species and ecosystems or the properties of ecosystems such as diversity, stability and integrity. However, the protection of ecosystems may still be central, since sentient or human beings depend on ecosystems in various ways for their survival and well-being. This position is sometimes called anthropocentrism, which is really a misnomer. The feature that unites this family of theories of value is not that they necessarily give priority to human interests (which is suggested by the label). To be sure, there are theories within the family that do, such as perfectionist theories of an Aristotelian kind founded on ideas about human nature or Kantian theories founded on the doings and treatment of rational beings.<sup>55</sup> However, other theories that hold environmental values to be instrumental deny that morality prioritises humans. One obvious example is hedonistic utilitarianism, according to which the pleasure and displeasure of all sentient beings are equally morally relevant. I will thus call this position *environmental instrumentalism*.

On the other hand, there is *eco-centrism*. Eco-centrism is really a label for a family of theories which are united by claiming that entities such as species and ecosystems or the properties of such entities are intrinsically valuable. Different

theories within this family hold that different states of affairs, entities, or properties of entities possess intrinsic value. Some claim that species do,<sup>56</sup> others claim that ecosystems do,<sup>57</sup> yet others that the properties of such ecosystems do, such as diversity, stability and integrity.<sup>58</sup> Thus, all these positions claim that abstract or collective entities, such as “biotic wholes”, are intrinsically valuable, regardless of the experiences and attitudes of feeling and thinking beings. Of course, this is *highly* controversial. Nonetheless, for the sake of the argument, I will not take a stand on the plausibility of these theories, but grant that some of them, or some combination of them, may be true.

Another version of eco-centrism, often combined or confused with the above-mentioned versions, claims that states of affairs or organisms are intrinsically valuable because they are in some way *natural* or, at least, that unnaturalness is intrinsically bad.<sup>59</sup> This idea is one of the most contested in debates on GMO and is regularly criticized for resting on a variety of fallacies and misconceptions. For one thing, it seems to make the naturalistic fallacy by inferring an “ought” from an “is”: just because something is unnatural (as a matter of description), it does not have to be bad (as a matter of moral).<sup>60</sup> Moreover, it is unclear where the line between natural and unnatural should be drawn; unless “unnatural” is not identified with “against the laws of nature”, in which case nothing is unnatural, not even GMO.

This criticism has been claimed to be off the mark, unfairly depicting sceptics’ understanding of GMO as conceptually confused. To be sure, “naturalness” is ambiguous term, which can be interpreted in clear, substantial, and perhaps even morally relevant ways.<sup>61</sup> For instance, in a sense, all GMOs are artefacts,<sup>62</sup> which roughly means that they are the result of intentional human action. And it may be argued that this makes GMO instrumentalized in a morally problematic way. In fact, the basis of much of the scepticism seems to be a worldview, which primarily opposes “instrumentalization of the nonhuman world”.<sup>63</sup> I think that one way to accommodate this scepticism is by analogy to the Kantian Formula of Humanity,<sup>64</sup> but regarding nature: we should not treat nature merely as an instrument or means for our own purposes. Perhaps it can be argued that changing the DNA of some organism in nature by GMO-technology amounts to illegitimately treating nature as a means for one’s own purposes. Perhaps GMO is unnatural in some other morally relevant way. Frankly, I have no idea whether this is so. However, for the sake of the argument, I would like to give the radicals as much ammunition as possible and still prove them wrong. Thus, I will assume that GMO may be unnatural in a manner that contributes to its intrinsic disvalue.

However, unnaturalness, like other intrinsic values, may come in degrees. For instance, it has been claimed that intragenic modification is less unnatural, e.g. by “respecting the ‘otherness’ of nature” to a higher degree, than transgenic modification (i.e. crossing species boundaries).<sup>65</sup> It may, of course, be claimed that all GMO is equally unnatural and, thus, equally bad. However, I think the intuition that unnaturalness is bad is often combined with the intuition that there are degrees of unnaturalness – a transgenic crossing of humans and fish, if that were possible, resulting in a creature which looks like a human with a fish tail instead of legs

would probably be considered more unnatural than some *e. coli* bacteria with one gene knocked out. This is important to keep in mind, since it implies that reasons in terms of naturalness may be more or less strong, just like reasons in terms of other alleged values, such as health and well-being.

## 5 Radical Prohibitionism

Now, recall the radicalism of Radical Prohibitionism: this was the position that the commercial marketing of GMO should *never* be permitted *under any circumstances*. Just like the case with Radical Libertarianism, this requires a principled defence. The only way to provide such a defence is to claim that some kind of *intrinsic* value that GMO would *always* destroy or some *intrinsic* disvalue that GMO would *always* realize *always overrides* other *kinds* of values that GMO may promote.<sup>66</sup>

Why do the values the GMO destroy need to be of a different kind from the values that GMO may realize? If GMO may realize similar kinds of values as they destroy, then it is a matter of the extent to which the value in question is destroyed in comparison to the extent to which the value is realized. This is not to presuppose that all values are precisely comparable or can be measured in any valid or reliable way. On the contrary, I believe all values are roughly comparable at best. However, if we reformulate talk about values as talk about reasons, we will see more clearly that comparisons in terms of the same value are at least *possible*, at least *roughly*, and at least *sometimes*. For instance, if one *knows* that the production and selling of a GMO-product will promote the health of a million people to a very large extent and only damage the health of one person to a very small extent, the reasons in terms of health to produce and sell the GMO-product in question are certainly stronger than the reasons in terms of health not to produce it. Whether we have such knowledge or not and whether there are such GMO-products or not are contingent matters, not a matter of principle. Thus, if the commercialisation of some GMO-product can realize exactly the same kinds of values and disvalues, it is a contingent matter whether there is more reason to allow this commercialisation than not depending, of course, on the kinds and amounts of values and thus the strength of reasons in question. So in order to defend Radical Prohibitionism successfully, one must establish that GMO *always* destroy a kind of value that they never promote.

This is why clarifying the distinction between versions of eco-centrism claiming that species, ecosystems, biological diversity, stability, and integrity is intrinsically valuable and versions that (also) claim that naturalness is good or unnaturalness is bad is of great importance. It is only the second kind of eco-centrism that can offer a principled and general argument against the commercial marketing of GMO. It is at least *conceivable* that genetically modified organisms can be used to prevent the extinction of species, preserve ecosystems, or promote the diversity, stability, and integrity of an ecosystem. For instance, a GMO-vaccine, or a GMO-plant better equipped to handle the impact of human contamination, can save members of a species on the verge of extinction, and thereby perhaps contribute to the diversity, stability and integrity of an ecosystem. So the only eco-centric position that can

provide a principled defence of Radical Prohibitionism is the one claiming that there is something inherently bad with “unnatural GMO” in ecosystems.

However, reference to such a theory of value is not sufficient in order to defend Radical Prohibitionism. Moreover, showing that this kind of value is *either* wholly incomparable with *or* that it always overrides any other values that GMO may realize is necessary.<sup>67</sup> Otherwise, whether or not there are stronger reasons to allow the commercialisation of some GMO-product than not becomes a contingent matter depending, again, on the weight of reasons provided by the values and disvalues realized. Now, neither of these positions is easily defended. This is, once again, most obvious if the values in question are reformulated in terms of reasons.

To see the difficulty in defending the position that different kinds of reasons are wholly incomparable, consider the following example quoted from Parfit:

Suppose that we are choosing between some architectural plans for some new buildings. If economic and aesthetic reasons were wholly incomparable, this would imply that

- (1) we could rationally prefer one of two plans because it would make this building cost one cent less, even though it would be much uglier,  
and that
- (2) we could also rationally prefer one of two other plans because it would make this building slightly less ugly, even though it would cost a billion dollar more.<sup>68</sup>

When considering this case, concurring with Parfit’s conclusion that “it would be most implausible to claim that *both* these preference would be rational” is easy. However, the possibility that these preferences could be rational *at the same time* is implied by the claim that two types of reasons are wholly incomparable or incommensurable. Of course, the same line of reasoning is valid regarding any two types of reasons. If values as different as economic and aesthetic ones are, at least, partially comparable, as can be seen in Parfit’s example, understanding why other values that seem *prima facie* very different would not be is hard.

In fact, I would go further than Parfit: this example not only suggests that different kinds of values can be compared, at least in some circumstances, but also that it is implausible to claim that even the weakest reasons of one kind can never be outweighed by the strongest reasons of another kind. That is, not only is claiming that different intrinsic values are wholly incomparable is implausible, claiming that one kind of intrinsic value is lexically prior to all other intrinsic values in all situations is also implausible. To further support this point, consider the following example. Suppose that we are considering whether or not to allow the production and marketing of some slightly genetically modified crop. Suppose further that all GMO is unnatural and that that this unnaturalness is an intrinsic negative value, i.e., that there always is a *pro tanto* reason against producing GMO. Remember that values may come in degrees. Suppose further that the GMO in question could radically improve the health of a million persons, e.g. by containing some combination of fats and vitamins that would be otherwise unavailable to them. If the disvalue of unnaturalness, and thus the corresponding reason not to produce the GMO in question, always would override any value, e.g. health, this would imply

that we should rationally prefer that the GMO in question is not produced because it would involve a slight modification of its genome, even though it would alleviate the malnourishment of a million persons.

However unlikely and farfetched this example may be thought to be, it demonstrates the difficulty in showing one kind of reason *always* outweighs another kind. Since claiming that the negative value of unnaturalness always overrides all other values that may be realized by some GMO-products seems implausible, it must be a contingent matter whether or not some GMO should be produced depending, once again, on the weight of reasons provided by the values and disvalues realized.<sup>69</sup>

If this line of reasoning is sound, I have just destroyed a philosophical straw man, namely the Radical Prohibitionist. To my knowledge, no one has ever been radical to the extent that the Radical Prohibitionist is, at least not in a philosophical context. Those who oppose the allowance of commercial marketing of GMO probably do so for other and better reasons than by reference to some alleged overriding negative value that GMO always realize.

Of course, one less radical way of being a prohibitionist is to deny that the value of allowing the marketing of any GMO-product is outweighed by the disvalue of such an allowance, *as circumstances actually are*. However, even if a defence of such a position were to be successful, it would have obvious limitations. The following assumption seems plausible: which values and disvalues the marketing of GMO-products will realize will vary from case to case, depending on the properties of the GMO and on societal and other circumstances. For instance, the benefits of golden rice are at least *more* obvious than the benefits of some of the modified rape that are resistant to all herbicides but the one made by the same company that produces the rape. If one grants this assumption, then one has, also as a prohibitionist, to grant that the reasons for allowing some GMO-products may outweigh the reasons for not allowing them, at least in the future. A similar line of reasoning can be applied to societal circumstances: much of the resistance towards GMO seems to be more against the rules of patenting surrounding GMO than the GMO-products themselves. If this is the basis of resistance, then one has to grant that if these rules were to change, the reasons for allowing some GMO-products may outweigh the reasons for not allowing them.

Another less radical way of arguing in favour of a prohibitionist stance, which is one of the most common, is not by reference to the disvalues GMO-products *will* realize but disvalues that they *may* realize. That is, the argument refers to our *uncertainty* with regard to the possible effects of GMO. Naturally, much of the debated precautionary principle should be understood against this background.<sup>70</sup> The precautionary principle is formulated in many more or less diverging and more or less (often less) precise ways. As far as I can see, the claim common to all these formulations is that if there are foreseeable risks to health and environment then something should be done about them, even if the risks are insufficiently substantiated.<sup>71</sup> This is often taken to mean that even if scientific uncertainty about a potential threat exists, politicians should still take measures to prevent the threat, e.g. by banning a certain practice such as producing GMO.

The precautionary principles thus involve concepts of threat or risk. These concepts consist of at least two discernable components: one knowledge-components (regarding the likelihood of some event) and one value-component (regarding the value of some event).<sup>72</sup> There are those who claim that precautionary principles essentially involve a reference to certain values, typically values other than human well-being, such as eco-centric ones.<sup>73</sup> However, there are formulations of the principle that are compatible with environmental instrumentalism,<sup>74</sup> that is, the principle does not *presuppose* that naturalness or entities such as ecosystems are *intrinsically* valuable. In other words, the precautionary principle leaves open the question of the ultimate justification of environmental concerns.

Nonetheless, the precautionary principle *can* be combined with eco-centrism. Moreover, since precautionary principles seem to imply that we should pay extra attention to risks, possible negative values seem to be more important than possible benefits.<sup>75</sup> Since it probably gives more weight to potential disvalues than potential values or benefits, reference to some precautionary principle would give more weight to some reasons against allowing the commercial marketing of GMO. However, this kind of prohibitionist defence also has obvious limitations. If risks are reduced in various ways, more knowledge about possible effects attained and so on, precautionary principles could be consistent with allowing the marketing of some GMO-products. In fact, if a certain GMO-product is likely to *reduce* some risk, e.g. for some disease, precautionary principles can support its allowance, since not doing so would be to fail to take measures in order to avoid risks.

## 6 Concluding Remarks

If the argument presented is sound, what practical conclusions can be made regarding the allowance of commercial GMO? They are not as precise as one might hope because the argument leaves the matter of what is normatively relevant as well as the matter of what will in fact happen given different systems of regulation open to reasonable disagreement. However, the argument so far in conjunction with some general observation regarding present knowledge about GMO speak in favour of the following conclusion: treating GMO as a homogenous group that can be assessed similarly regardless of the individual characteristic of different GMOs is difficult.

On the one hand, a general opposition to the commercial production of all GMO seems hard to defend. There is hardly any opposition against genetically modified microorganisms used in the production of pharmaceuticals, such as insulin and growth hormones.<sup>76</sup> And it is hard to imagine any opposition to genetically modified *Pseudomonas*-bacteria better equipped to disperse oil slicks than all non-modified counterparts.<sup>77</sup> Even if opposition to genetically modified food is more widespread than opposition to genetically modified pharmaceuticals, some GM foods seem unaffected by such criticism, e.g. the “vegetarian cheese” containing recombinant chymosin, which has been on the market for quite some time.<sup>78</sup> The

general observation that there is extensive knowledge about the environmental and health effects of at least some GMOs and that GM food is often tested to an extent that no non-GMO food has ever been tested<sup>79</sup> should furthermore at least be recognised by those who are sceptical of GMO production and sales.

On the other hand, general approval for the commercial production of all GMO seems equally premature. It has to be recognised that it is seldom presently possible to give a comprehensive picture of all the potential impact on the environment from the release of genetically modified microorganisms, for instance since there is no unanimously accepted standard for profiling pre-release microbial populations. And a pathogenic organism could potentially pick up an antibiotic resistant GMO, ultimately causing unpreventable disease in organisms, e.g. humans. Even though our knowledge regarding some GMOs is well documented, this is not the case for all GMO. So even though claiming that we do not know anything about the benefits and risks of various GMOs is foolish, claiming that we know all there is to know or that there are no serious risks with no GMOs would be equally foolish.

Thus, on the basis of the above argument and these general observations, the following conclusion seems credible: the more one draws towards one of the radical positions, the more difficult it becomes to provide a plausible defence. Instead, considerations of which GMOs should be allowed for commercial production should be determined on a case-by-case basis, taking into account the benefits and risks of the GMOs in question. This should be granted even if one holds that there is something inherently bad with GMO. For even if so, the benefits of some GMOs may outweigh the problems.

In order to avoid misunderstandings, let us be clear on what I am *not* trying to say. I am not trying to say that allowing some GMO-products is reasonable, because they would realize more benefits than disvalues. I have no idea whether this is the case. I am a philosopher, not a seer or even a scientist. Perhaps the most reasonable thing to do today is to await more research before allowing the commercial marketing of more GMOs. Neither am I taking a stand on what values or rights that should ultimately be taken into account. This is the very question at the heart of moral philosophy and as such cannot be settled in this short essay (although I indicated what values may be the most important on at stake). In a multi-cultural and morally pluralistic society, this is one of the questions that should be the focus of attention. Since the answer to this question is crucial to the question of where in the middle ground to draw the line more closely between what should be allowed or not, I cannot take a definite and particular stand on that issue either. What I am saying is that the discussion about whether to oppose or support the commercial marketing of GMOs should end. If I am right, we can ignore such binary positions and discuss more interesting questions, such as which values are important and why, and which are the institutional and environmental circumstances that must be taken as given before the production and marketing of different GMO-products should be allowed. So this is really a call against quick fixes both in theoretical and applied ethics: in theoretical ethics against those who claim that one type of reasoning always overrides another, and in the GMO debate against those who want to either oppose or promote GMOs, period.

## Notes

<sup>1</sup> Since we are dealing with the question of what should be allowed, it is a matter of what legal system or regulation that is justified. Justified in what sense? In the sense that the balance of reasons all-things-considered speak in favour of a certain regulation, taking into account everything that is of normative relevance (whether it is rights, values, interests or something else).

<sup>2</sup> GMO should be read “genetically modified organisms” or “genetically modified organism”, i.e. as singular or plural depending on context. When I wish to emphasise that I am talking about different genetically modified organisms, I write GMOs.

<sup>3</sup> See e.g. Myhr and Traavik, 2003, pp. 322–323, and Reiss, 2001, p. 184.

<sup>4</sup> Questions about genes and patents have been meritoriously discussed elsewhere: see e.g. Wilkinson, 2003, pp. 182–221.

<sup>5</sup> See e.g. Singer, 1986.

<sup>6</sup> Such as the general argument that all intrinsic values can be compared to some extent.

<sup>7</sup> As late as June 2006, some Members of the European Parliament presented a Written declaration condemning all use of genetically modified food, seeds or fodder (Wojciechowski et al., 2006). However, prohibitionism of a radical sort has also been defended in more academic contexts, perhaps most notably by Jeremy Rifkin (see Palfreman, 2001).

<sup>8</sup> See e.g. Parekh, 2004, *passim*.

<sup>9</sup> See e.g. Schumpeter, 1943, and Dahl, 1956.

<sup>10</sup> See e.g. Launis and Siipi in this volume.

<sup>11</sup> One such idea is that decisions should have a certain content in order to be good from a democratic viewpoint, e.g. that they should respect “democratic rights”, such as freedom of speech, the right to form organizations, and so on. Some would even say that decisions lacking in such respects *cannot* be democratic (as a matter of definition). Besides leading to fruitless terminological discussions about what democracy “really is”, this last position seem to me to conflate definitions (what democracy is) with ideals (what is good democracy or how democratic societies should look like). For general discussions about various definitions and ideals of democracy, see Dahl, 1989, and Tännsjö, 1992.

<sup>12</sup> See e.g. Årmason in this volume.

<sup>13</sup> Dahl, 1989.

<sup>14</sup> Morris, 1973.

<sup>15</sup> Tännsjö, 1992.

<sup>16</sup> *Ibid.*

<sup>17</sup> See Lagerspetz in this volume.

<sup>18</sup> At least in Europe with respect to GM food (Stemke, 2004 p. 108).

<sup>19</sup> See Dworkin, 1977, Juth, 2005, pp. 214–225, Kagan, 1989, pp. 216–230, and Thomson, 1990.

<sup>20</sup> It is almost always presupposed that reasons connected to negative rights concern *all* others (see Häyry and Takala, 2001, p. 404).

<sup>21</sup> For an argument in favour of analysing negative and positive rights in terms of corresponding reasons for action rather than duties to act, see Juth, 2005, p. 218. See also Rääkkä, 1998, p. 58.

<sup>22</sup> Reiss, 2001, p. 188, suggests that ethical arguments in favour of subsidizing minority food (Rippe, 2000) might be extended to GMO-food. If such an argument were successful, there would be reasons to assist the minority who prefers GMO-food to purchase that food, i.e., a kind of positive right to GMO-food.

<sup>23</sup> Thus, we are dealing with *privileges* in Hohfeld’s right-parlance. According to Hohfeld, if someone, P, has a privilege regarding some action, A, this means that P has no obligation to abstain from doing A. However, from this we cannot conclude that Q does not have the privilege to prevent P from doing A. That is, P violates no one’s right if she does A, but Q may still be free to prevent P from doing A. Perfectly in line with standard liberal ideas to allow other commercial enterprises to “prevent” some commercial enterprise, C, from producing and selling GMO-products by competing with them on a market, making it unprofitable for C to offer the products in question. In such a situation, C would only have a privilege in the Hohfeldian sense, then.

<sup>24</sup> Although this will not be systematically demonstrated here, other theories in this family support the same conclusions in this respect as Nozick's, e.g. Gauthier's theory of morals by agreement (see instead Gauthier, 1986, Kymlicka, 1990, p. 132 ff, and Holtug, 1999, p. 288). Certainly, there are versions of libertarianism that recognize other types of normative considerations, e.g. persons' interests regardless of their rights (see Steiner, 1994). However, because of this, these theories cannot provide a principled defence of Radical Libertarianism (see the rest of this section).

<sup>25</sup> Nozick, 1974, p. 151.

<sup>26</sup> Of course, one can ask whether the original acquisition of previously unowned nature is legitimate when this nature is modified by genetic means. Personally, I cannot see why this kind of modification would be more problematic than other kinds from a libertarian point of view, but even if that were the case, it would make the argument against Radical Libertarianism much easier since it would mean that this position could never consider genetically modified organisms to be legitimate property.

<sup>27</sup> Nozick (1974, pp. 28–35) expresses this thought by saying that rights constitute *side constraints* to our actions. However, since even Nozick may allow for exceptions in case of "moral catastrophes" (Nozick 1974, p. 48), the extent to which even libertarianism would support Radical Libertarianism regarding GMO remains unclear.

<sup>28</sup> Nozick, 1981, p. 502.

<sup>29</sup> Wolff, 1991, p. 22.

<sup>30</sup> See e.g. Dworkin, 1977, Rawls, 1972, and Thomson, 1990.

<sup>31</sup> See especially Dworkin, 1977.

<sup>32</sup> See e.g. Juth, 2005, pp. 414–415 and Kymlicka, 1990, pp. 96–97.

<sup>33</sup> See e.g. Gren, 2004, pp. 141–142, and Nozick, 1974, p. 231.

<sup>34</sup> See e.g. Cohen, 1986, Holtug, 1999, p. 289, and Kymlicka, 1990, p. 113.

<sup>35</sup> Nozick, 1981, Chapter 5.

<sup>36</sup> See Nozick 1974, and 1981.

<sup>37</sup> Of course, there is a theoretical possibility of founding Radical Prohibitionism upon rights as well, e.g. the rights of genes and plants. Although I fail to see the benefits of such a foundation, it is irrelevant to my argument, since both rights and values can be analyzed in terms of reasons. The question thus always remains: what do we have more reason to do and decide, regardless of whether these reasons are cast in terms of values or rights.

<sup>38</sup> For instance, claims that genetically modified wheat has reduced the use of pesticides in the USA by 25% have been made (Svedin, 2001).

<sup>39</sup> Clark and Lehman, 2001.

<sup>40</sup> Parekh and Gregg, 2004, pp. 13–14.

<sup>41</sup> *Ibid.*

<sup>42</sup> Those critical of the "world starvation"-argument for GMO claim that the problem is not lack of GMO, but global injustice. Even though true, one can question the relevance of this argument: why not take the measures we can to alleviate world starvation even if there also are other measures that could be taken against world starvation, measures required by justice.

<sup>43</sup> Myhr and Traavik, 2003, p. 324.

<sup>44</sup> For this kind of aesthetic resistance towards GMO-agriculture, see Deckers, 2005, p. 471.

<sup>45</sup> Gebhard and Smalla, 1999.

<sup>46</sup> That is, something that inherits its value by causing, or being a necessary precondition, or the like for something that is of value in itself. That is, instrumental values in this context are understood rather widely, as being synonymous with extrinsic value (Brülde, 1998, pp. 388–390).

<sup>47</sup> I interpret intrinsic value as something being valuable because of its intrinsic properties. However, some want to distinguish between intrinsic and final values (Brülde, 1998, pp. 388–390), since there may be things that should be valued for their own sake, but which are not valuable because of their intrinsic properties (e.g. something that is valuable because of its relational properties, e.g. being the first manufactured object of some kind). If one favours such a possibility, intrinsic value should be interpreted as referring to the final value in the following.

<sup>48</sup> See e.g. Kagan, 1989, p. 61 and Tännsjö, 1998, p. 119.

<sup>49</sup> One view says that X is intrinsically valuable if, and only if, X has properties that gives anyone a reason to have a pro-attitude towards X for its own sake (a so-called "buck passing"-theory of intrinsic

value, see Scanlon, 1998). Another view is the Moorean idea that X is intrinsically valuable if, and only if, X's value supervenes on the intrinsic (or non-relational) properties of X (Moore, 1903), and add that anyone has a pro tanto reason to promote X if X is intrinsically valuable.

<sup>50</sup> To be sure, there are those denying that anything has intrinsic value and there are those who claim that all values agent-relative (only values-for-someone). But I challenge anyone to find a single influential philosopher who would claim that *being valuable in itself* gives *no one any reason whatsoever* to promote that which is valuable in some way, if the relevant agent could do so.

<sup>51</sup> Brülde, 1998, p. 296.

<sup>52</sup> Brülde and Tengland, 2003.

<sup>53</sup> At least since Parfit (1984, pp. 493–502) distinguishing between three main theories of well-being: *hedonism*, desire fulfilment theories or *preferentialism*, and *objective list theories* or *perfectionism* has been customary, even though the vocabulary differs somewhat between writers. See e.g. Brülde, 1998, Kagan, 1998, pp. 29–41, and Temkin, 1993, pp. 258–280.

<sup>54</sup> Of course, one may claim that there are no intrinsic values in the sense that there are no empirical properties (e.g. happiness) that we always must promote. Instead, one may claim that what constitutes a value may vary from situation to situation, i.e. *particularism* (Dancy, 1993). One may also claim that there are no values whatsoever, i.e. *nihilism*. See endnote 64.

<sup>55</sup> Strictly speaking, even these theories deny that there is a morally relevant distinction between human beings as such and other beings, since they only include a subclass of human beings, e.g., rational humans or those who can realize their potential as human beings (which would exclude some humans with severe mental disabilities).

<sup>56</sup> Rolston, 1995.

<sup>57</sup> Callicott, 1989.

<sup>58</sup> See e.g. Leopold, 1991 and Rolston, 1994.

<sup>59</sup> For instance, it has been claimed that e.g. diversity is good only if it is natural (Angermeier, 2000).

<sup>60</sup> Thompson, 1997, p. 35.

<sup>61</sup> This is convincingly argued in Siipi's thorough and lucid dissertation (2005) about naturalness and related concepts in bioethical discourse.

<sup>62</sup> More precisely, GMOs are artefacts in the sense that all species of GMOs and the first generation of all individual GMOs are artefacts (Siipi, 2005, pp. 100–105).

<sup>63</sup> Deckers, 2005, p. 451. See also Scott, 2000, for an analysis of the basis and worldview underlying the green movements resistance to GMO on similar grounds.

<sup>64</sup> "Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means but always at the same time as an end" (Kant, 1785, p. 429).

<sup>65</sup> See, Myskja, 2006.

<sup>66</sup> If particularism is true, then demonstrating that it is a contingent matter whether or not some GMO should be permitted is even easier, since what is valuable or otherwise morally relevant would differ from situation to situation. If nihilism is true, then no particular position would follow. See endnote 52.

<sup>67</sup> Whether the position that the value of naturalness is wholly incomparable with other values could be used to provide a rationale for the Radical Prohibitionism is highly doubtful, since such an idea would be consistent with claiming that ignoring the naturalness of something if it realizes other incomparable values is not irrational. However, for the sake of the argument, I will allow this way out for Radical Prohibitionism.

<sup>68</sup> Parfit, 2006, p. 62. I would like to thank the author for permission to quote from an unpublished manuscript.

<sup>69</sup> In fact, influential eco-centrists would concur to the idea that even if naturalness is a value, it is not the only one and that trade-offs between naturalness and other values are reasonable (Elliot, 1992, pp. 138–139). For some, this is so plausible that it can simply be assumed (Siipi, 2005, pp. 15–16). Naturally, I concur.

<sup>70</sup> See Ahteensuu in this volume.

<sup>71</sup> For an argument in favour of this position, consisting of numerous formulations of the principle, see Sandin, 1999.

- <sup>72</sup> These components are equivalent to the damage threshold and the knowledge threshold that constitutes the trigger conditions for precautionary response (see Ahteensuu in this volume).
- <sup>73</sup> Mayer and Sterling, 2002, pp. 60–61.
- <sup>74</sup> Perhaps most notably in the Rio Declaration (UNEP, 1992), where sustainable development for the sake of human beings is the overarching value (see, e.g., Article 1). See also the formulations in Ahteensuu in this volume.
- <sup>75</sup> This last idea is obviously connected to the intuition of the weight of evil.
- <sup>76</sup> Stemke, 2004, p. 108.
- <sup>77</sup> Stemke, 2004, p. 114.
- <sup>78</sup> Stemke, 2004, p. 110.
- <sup>79</sup> Stemke, 2004, p. 108. Furthermore, up to date, no GM food has been proven to damage health more than non-GM counterparts, despite extensive testing.

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# The Precautionary Principle and the Risks of Modern Agri-Biotechnology

Marko Ahteensuu

## 1 Introduction

Much of the recent discussion about the acceptability of modern biotechnology research and its practical applications has been concerned with risk and safety issues. What and how severe are the risks of modern biotechnology? How should we respond to the threats in ethically sound manner? How safe is safe enough? Differing responses to these questions have created a heated and still ongoing debate in which a great variety of stakeholders have participated in various arenas. Contributors include lawmakers and policymakers;<sup>1</sup> independent research institutes such as the Food Ethics Council;<sup>2</sup> scientists from a range of disciplines;<sup>3</sup> several environmental organisations;<sup>4</sup> and laymen, for instance, in consensus conferences.

In this ongoing debate, modern biotechnology research and its practical applications have been opposed due to the risks these activities engender.<sup>5</sup> Appeals to the alleged threats in order to justify limitations are examples of risk arguments. Risk arguments are conditional, i.e. they warrant restrictions only if the activity in question actually imposes an unacceptable risk.<sup>6</sup> Whilst constraints on an activity can be justified on the basis of its known and predicted negative consequences, limitations may also be premised upon the possible inherent moral wrongness of an activity regardless of the effects. As an example of the latter, that is categorical arguments, genetic engineering has been claimed to be against God's will (or playing God) because of violating fundamental boundaries set by God, and thus unconditionally intolerable.<sup>7,8</sup>

The precautionary principle has a central role in the debate on the well-grounded risk governance of modern biotechnology.<sup>9,10</sup> Risk arguments referring to threats which are poorly understood in scientific terms and/or which are matters of scientific disputes are typically founded on this principle. In order to evaluate these arguments rationally, one must comprehend the nature of the risks in question, and what is meant by the precautionary principle. In what follows, I will briefly discuss the alleged risks of modern agri-biotechnology, after which I shall try to explicate

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M. Ahteensuu

Department of Philosophy at the University of Turku, Finland  
e-mail: mataah@utu.fi

the precautionary principle. Two opposite views on the right role of the precautionary principle in the agri-biotech risk governance are subjected to critical analysis. Finally, a middle stance is suggested. The aim of this paper is not to present strong conclusions or ideological views,<sup>11</sup> but on the one hand to suggest a shift in the focus of the academic debate over the precautionary principle, and on the other hand to provide conceptual and ethical tools for non-specialists to form reasoned beliefs and attitudes towards the risk governance of modern agri-biotechnology.<sup>12</sup>

## 2 The Risks of Modern Agri-Biotechnology

Although the term “risk” has multiple definitions and uses, generally speaking it refers to exposure to the chance of loss. More precisely, a risk denotes an undesirable state of affairs which may or may not occur as a result of human activities and/or natural events.<sup>13</sup> Accordingly, distinguishing between *anthropogenic* and *non-anthropogenic* threats is common.<sup>14</sup> Whilst technological risks such as the risks of modern agri-biotechnology are examples of the first-mentioned, natural disasters that are due to asteroid impacts, earthquakes, typhoons, plagues and so on can be subsumed under the latter category.<sup>15</sup> Because anthropogenic threats comprise a human contribution by definition, the ethical responsibility for preventing these disasters from taking place is strengthened.

The risks of modern agri-biotechnology are instances of *societal* risks which may be contrasted with *individual* risks. Roughly speaking, the latter ones are chosen such as active smoking and its possible negative consequences, whereas in the first case the possibilities of an individual to affect her/his exposure to the risks are more limited.<sup>16</sup> It should be noted, however, that the distinction is a matter of degree, not of a qualitative difference. As an example, individuals have power over their exposure to genetically modified (GM) foods, for instance, owing to labelling requirements. Governments typically regulate the production of societal risks. Societal risk decision-making is presumed to be transparent, proportional and non-discriminatory, and based upon (commonly accepted) adequate grounds.

As is characteristic of technological threats, the risks of modern agri-biotechnology are multidimensional and complex in nature. They consist of numerous possible environmental, health, economic, aesthetic and other societal impacts. In this respect, traditional analytic approaches to risk, which may be described as quantitative and reductive in nature, seem to be insufficient and even invalid. Risk has typically been understood narrowly as a function of two variables, i.e. as a numerical value of quantified magnitude and of probability of a loss. In contrast, the multiple features of technological risks may be irreducibly qualitative in nature. Furthermore, different risks might be incommensurable.<sup>17</sup>

Despite the great variety of possible and known impacts of modern agri-biotechnology, the most heated scientific debates have been concerned with the possible environmental damage and the possibility of health hazards.<sup>18</sup> A number of studies on the environmental and other wildlife impacts of GMOs

have been conducted.<sup>19</sup> Nonetheless, uncertainties on complex (or higher-order) interactions and interdependencies, and on potential unexpected, cumulative and delayed effects still remain.<sup>20</sup> For instance, genetic engineering may result in unintended consequences on plant metabolism. According to the *Ecological Society of America*,

deliberate or inadvertent releases of GEOs [genetically engineered organisms] into the environment could have negative ecological effects under certain circumstances. Possible risks of GEOs could include: (1) creating new or more vigorous pests and pathogens; (2) exacerbating the effects of existing pests through hybridization with related transgenic organisms; (3) harm to nontarget species, such as soil organisms, non-pest insects, birds, and other animals; (4) disruption of biotic communities, including agro-ecosystems; and (5) irreparable loss or changes in species diversity or genetic diversity within species.<sup>21</sup>

The shortage in scientific knowledge concerning the long-term environmental effects of GMO releases has been stressed on several occasions.<sup>22</sup>

When compared with wildlife experimental studies, peer-reviewed articles on the adverse health effects of the GM foods are relatively scarce.<sup>23</sup> The risks might include toxic and other adverse effects such as threats of more vigorous diseases and an increase in allergies. Whether or not the new genes inserted into GM plants could be incorporated into the genome of consumer has been debated. Although no direct evidence that complete genes have ever been transferred to human beings through nutrition (traditional<sup>24</sup> or GM foods) exists, there is evidence that plant and gastrointestinal DNA can transfer to mammalian and bacterial cells. At least, fragments of transgenes can survive through the stomach and small intestine, and they can transfer to gut bacteria in the human gut.<sup>25</sup> The validity of extrapolation from animal studies has been contested, however. A threat arises from the possible emergence of new antibiotic-resistant pathogens. This could take place if the antibiotic-resistant marker genes<sup>26</sup> in the GM food consumed were to transfer to bacteria in the consumer's alimentary canal and accelerate a trend toward antibiotic-resistant pathogens. Given this possibility, it should be borne in mind that antibiotic-resistant bacteria also emerge without the use of gene technologies,<sup>27</sup> and that they may spread through the consumption of traditional foods as well.<sup>28</sup>

Allergic disorders, in turn, occur through contact, nutrition or inhalation (of pollen and dust). It is possible – although highly improbable – that GMOs will result in increased allergenic potential. For instance, genes transferred from foods to which certain people are allergic may elicit allergic reactions in those particular consumers of GM food with pre-existing allergies. Novel proteins which an organism has (un) intentionally been enabled to produce, and which have never been a part of the human regimen, are also potential allergens. Nevertheless, although our ability to predict the allergenic potential of GM foods may still be limited, “there is almost no scientific evidence that genetically modified organisms (GMOs) exhibit increased allergenicity compared with the corresponding wild type”.<sup>29</sup>

Lastly, unexpected effects sometimes occur in the natural environment (which includes the human body and bodily functions). Their possibility cannot be completely ruled out by the means of science. Yet it should be emphasised that this fact is not restricted to the risks of modern agri-biotechnology.

The precautionary principle is called into play by two facts about the current state of scientific knowledge on the risks of modern agri-biotechnology. First, there are uncertainties – some, as noted, even extensive – concerning the health hazards and long-term environmental threats. Some of the threats remain poorly understood in scientific terms. Second, several alleged risks are matters of ongoing scientific disputes.

### 3 The Precautionary Principle

The precautionary principle is a principle of practical decision-making which may be justified on the basis of ethical and socio-political grounds and/or as a form of rational action. It is commonly invoked in societal risk governance. The core idea of the principle can be stated as follows: serious environmental threats and health hazards should be anticipated (*foreseen*), and they ought to be prevented (*forestalled*) before the damage comes to fruition, even if scientific understanding of the risks is inadequate.

*Origin and Development.* The origin of the precautionary principle has been traced to different sources. Sometimes it is argued that the roots of the principle can be found in the general and everyday idea of precaution.<sup>30</sup> No doubt, taking precautions is instinctive for human beings, and it is certainly in accordance with common sense. The essence of precaution is captured in several English sayings, such as “better safe than sorry” and “an ounce of prevention is worth a pound of cure”. Others have traced the history of the precautionary principle to specific (non-judicial) arguments from precaution which have been presented, for instance, by certain social scientists in 1970s and 1980s.<sup>31</sup>

It is also claimed that formalised forms of the precautionary principle have been employed in the standard decision theory,<sup>32</sup> and that the basic idea of precaution can be found in the current and/or former policies and ethical codes of conduct, e.g. in public health policy. It is even argued that the first reference to the precautionary principle was the Hippocratic Oath “*primum non nocere*”.<sup>33,34</sup> The common denominator in all the above-mentioned attempts to illuminate the origin and history of the precautionary principle is the absence of an explicit reference to the term “the precautionary principle”. Hence, the application of the principle has been projected onto these sayings, arguments and policies retrospectively.

Lastly, seeking the origin of the precautionary principle from law texts and other official documents is common. A predecessor of the precautionary principle can be found in *Vorsorgeprinzip* (foresight-planning) which was introduced to the German environmental policy and law in 1970s.<sup>35</sup> The first explicit mention of the precautionary principle in an international environmental treaty was approximately twenty years ago. The Ministerial Declaration of the *Second International Conference on the Protection of the North Sea* (1987) states that “in order to protect the North Sea from [the] possibly damaging effects of the most dangerous substances, a precautionary approach is necessary”.<sup>36,37</sup>

*Substantial Propositions.* Ethically speaking, three substantive propositions implied by the precautionary principle can be identified. First, environmental damage and health hazards should be anticipated, i.e. identified and assessed, before they actually take place. This normative demand reflects a plea to narrow the scope of our ignorance and oversight. Concrete risk research and the active development of its methods can certainly increase our ability to identify and assess environmental threats and health hazards, and can also tell us about what we do not know. However, there may always remain possible outcomes that we do not know that we do not know about. Trying to avoid these possible outcomes would be highly impractical (i.e. costly and resource-demanding) and partly impossible in principle. Second, the precautionary principle implies a norm to take pre-emptive actions in order to protect the environment and human health. This *proactive* view may be contrasted with the *reactive* approach which states an obligation to remedy or compensate damage after it has come to fruition. (Of course, one possible position would be to disregard these kinds of harms entirely.) The third substantial proposition concerns the appropriate role of scientific knowledge in the environmental and health policy. According to the precautionary principle, adequate scientific understanding of an identified threat is not a necessary condition for taking precautions.<sup>38</sup> This feature distinguishes the principle (or the precautionary approach) from earlier institutionalised risk governance approaches.<sup>39</sup>

*Paradigm Examples.* Despite the commonly agreed (general) core idea, the precautionary principle has various forms. A number of formulations can be found in official documents such as international environmental treaties,<sup>40</sup> and several definitions have been proposed in the academic literature related to the principle.<sup>41</sup> Nevertheless, two particular formulations may be considered paradigmatic. The most noted formulation of the precautionary principle is probably that adopted at the United Nations conference on environment and development in Rio de Janeiro. The so-called Rio Declaration (1992) states that

[w]here there are threats of serious or irreversible damage, lack of full scientific certainty shall not be used as a reason for postponing cost-effective measures to prevent environmental degradation.<sup>42</sup>

This formulation is explicitly mentioned in the bulk of the academic articles on the principle, and it is typically presented as a basic example.<sup>43</sup> Furthermore, the exact wording or a commitment to implement the formulation is included in several treaties and other official documents.<sup>44</sup>

The second standard formulation was introduced at a conference organised by the Science and Environment Health Network (SEHN) in 1998.

When an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically.<sup>45,46</sup>

According to Derek Turner and Lauren Hartzell, this formulation is “[t]he closest thing to a canonical version of the precautionary principle”.<sup>47</sup> Several environmentalists endorse the formulation.

*Basic Structure.* In addition to the clarification of the core propositions and identification of the paradigm examples, a basic structure as a decision-making principle can be abstracted. Specifically, every formulation of the precautionary principle is a function of two variables, namely that of a trigger condition and precautionary response. When a situation fulfils the prerequisites described by the trigger condition, the stated precautionary response should be taken.<sup>48</sup>

The trigger is two-fold. It consists of damage and knowledge thresholds which determine the necessary and jointly sufficient preconditions for the application of precaution. The damage threshold concerns harmful or otherwise undesirable outcomes. More specifically, the relevant types of harm include (1) environmental damage, e.g. loss of biodiversity; (2) human deaths and health hazards such as increased allergies; and (3) harm to other sentient beings. Other kinds of risks such as economic ones – if taken into account at all<sup>49</sup> – are considered only indirectly. Although certain formulations of the precautionary principle specify the relevant harms,<sup>50</sup> the interpretation of the damage threshold is ultimately determined by the general chosen level of protection, or alternatively by the agreed level of acceptable risk.<sup>51</sup>

The second element of the trigger is the knowledge threshold which defines the required level of scientific understanding (of an identified threat) at which the prescribed precautionary response is well-founded. A narrow view based upon a decision-theoretic classification suggests that the principle can be applied when (1) the (objective) probability of a risk cannot be established, i.e. in the state of scientific uncertainty, or when (2) the magnitude (or severity) of a risk is uncertain or contested, that is, in the state of ambiguity.<sup>52</sup> It has also been argued that the precautionary principle can be applied in the state of ignorance, viz. when neither the probability nor the magnitude of a threat can be assigned.<sup>53</sup> A broader view, which rests upon the level of scientific understanding, states that taking precautions is well-founded when a threat is poorly understood in scientific terms, or when there are scientific discrepancies and disagreements on the nature of a risk.

In the abstract, the sources of limited scientific understanding (of a risk) can be divided into three classes. First, uncertainty and disagreements arise from incomplete analyses that are due to such factors as gaps in the data or poor quality data. Second, the analysis methods used may be invalid. This can take place, for example, in the form of faulty models, assumptions, and extrapolations from evidence. The relevant, actual, causal pathways do not necessarily correspond to those identified and tested. Third, our knowledge can also be limited by the high complexity and indeterminacy of some natural systems. The human factor (i.e. decisions in the future), for instance, can significantly reduce the accuracy of our predictions.

The second structural part of the precautionary principle is the prescribed action. Precautionary response means taking pre-emptive measures. These may take the form of outright bans or phase-outs, moratoria, pre-market testing, labelling and requests for extra scientific information before proceeding. Another kind of precautionary response would be the establishment and implementation of new precautionary risk assessment methodologies. The last-mentioned reflects a heavy emphasis

upon the first substantial proposition of the principle – the focus is not only on how to deal with the identified threats, but also on the methods to anticipate and assess threats at the first place.<sup>54</sup>

## **4 Well-founded Risk Governance of Modern Agri-Biotechnology**

In this chapter, I will consider two conflicting answers to the question as to whether the precautionary principle should be implemented in the risk governance of modern agri-biotechnology. Much of the discussion has centred upon straightforward “yes” and “no” stances. An explication and critical analysis of these standpoints is followed by a suggestion to shift the discussion towards more plausible and interesting middle positions.

### ***4.1 The Precautionary Principle Should be Implemented in the Risk Governance of Modern Agri-Biotechnology***

The precautionary principle is widely embraced. Independent research institutes and a number of scholars have emphasised the importance and necessity of the precautionary principle in the well-founded risk governance of modern biotechnology.<sup>55</sup> The wide application of the principle has also been endorsed by several non-governmental organisations (NGOs), in particular environmental organisations such as Greenpeace, Friends of the Earth and the SEHN. Furthermore, the precautionary principle is explicitly mentioned in national biotechnology laws, and several governments have accepted the principle as a cornerstone in (environmental) policymaking.<sup>56</sup> In Finland, for instance, the reformed *Genetic Engineering Act* (2004/847) mentions the principle in the first paragraph. Moreover, the European Union (EU) has adopted the principle in its modern biotech risk governance.<sup>57, 58</sup> The precautionary principle was used as a justifying reason for the *de facto* EU Council moratorium on commercial approvals of the GM crops. (Between late 1999 and 2004 no authorisations were given.) In international law, the *Cartagena Protocol on Biosafety to the Convention on Biological Diversity* (2000), which regulates the transfer, handling and use of living modified organisms (LMOs), refers to the principle in its key objectives.<sup>59</sup>

The importance or necessity of the precautionary principle in the well-founded risk governance of agri-biotechnology can be defended on various grounds. Nevertheless, two broad classes of arguments are worth distinguishing. On the one hand, it has been claimed that the precautionary principle should be applied in all environmental and health risk decision-making. Consequently, the principle should also be implemented in agri-biotech risk governance. This view may be correctly attributed to several environmental organisations (e.g. to the SEHN). It is also worth mentioning that the precautionary principle has been incorporated into the EC Treaty since 1992 as one of the basic principles upon which all the Community’s environmental

(and health) policies should be based.<sup>60</sup> On the other hand, arguments which are specific to agri-biotech risk governance have been proposed.

There are several general grounds for the importance of the precautionary principle in environmental and health policymaking. First, owing to a number of factors such as the new possibilities provided by technological development, the stakes have become higher than before. Human action can lead, and has already contributed, to serious and irreversible environmental damage. Second, there is growing recognition of ecosystems' sensitivity as well as of their intra- and interdependencies. Our limited understanding of several natural processes and the related risks has increasingly been admitted and emphasised. Furthermore, the prevailing institutionalised risk governance methodology (esp. the quantitative risk assessment) has been subjected to substantial criticism. In this methodological approach, it is presumed that the strict boundary between scientific knowledge and unscientific beliefs (i.e. mere opinions or speculative guesses) is appropriate to the governance of environmental risks. Conclusive scientific proof has been used as a prerequisite for taking preventative measures. Notwithstanding this, there have often been weak indicators (or early "warnings") of damage before its materialisation. Because the available evidence for the threats has not fulfilled the strict criteria of scientific knowledge, real risks have been ignored with highly detrimental consequences.<sup>61,62</sup>

In contrast to the general arguments for precaution, new modes of irrevocability present a ground that might be unique to modern agri-biotechnology. If a GMO escapes into the environment or if a transgene flows into other organisms, it may be difficult or even impossible to reverse or to remedy the consequences. As Gary E. Marchant explains,

[u]nlike a chemical pollutant, where the amount of the pollutant released into the environment is fixed and will decline over time, a living biological "pollutant" has the potential to grow and reproduce without limits.<sup>63</sup>

Furthermore, there are risks inherent in the method of gene manipulation. Scientists are still unable to control the location of the transgene in the host genome, which may cause "unstable nature of the transgene and vectors used to insert it, and (. . .) unpredictable interactions between the transgene and the host genome".<sup>64</sup> This might result in unpredictable phenotypic effects.

Other factors which are characteristic of modern agri-biotechnology include, for instance, the growing public exposure to GM technologies and products;<sup>65</sup> the limited amount of peer-reviewed articles on the experimental studies on health effects;<sup>66</sup> the shortage of knowledge on long-term environmental impacts;<sup>67</sup> and, public concerns and distrust.<sup>68,69</sup>

*Problems.* The normative view that the precautionary principle should be implemented in the risk governance of modern agri-biotech suffers from several shortcomings. First, the precautionary principle has sometimes been interpreted and employed by policymakers and others in indefensible ways.<sup>70</sup> For instance, appeals to purely hypothetical risks without any scientific evidence in order to warrant restrictions as well as demands for zero-risk represent theoretically implausible interpretations of the principle. They should not be used in societal

decision-making. Moreover, taking completely cost-oblivious precautions may be rejected on practical grounds.<sup>71</sup> Second, in certain cases when the precautionary principle is implemented at the international level, it may be difficult to prove that precaution is not applied as “a disguised restriction on trade”.<sup>72</sup> Since taking precautionary measures is justified in the absence of evidence which counts as scientific in the strict sense, the boundary between environmental protection and unfair trade barriers becomes blurred. Third, the (contextual) threshold(s) for taking well-founded precautions is hard to define accurately, and it can always be intentionally disputed in order to promote interests which are unrelated to the environmental protection. Last, there is no guarantee that the most reliable science, and not the most radical one, is used as the basis of precautionary decision-making.<sup>73</sup>

In general, the precautionary principle leaves much space for discretion, and this may be misused. Despite the established policy documents and academic efforts to clarify the precautionary principle and its application, the principle has remained elusive and controversial.<sup>74</sup> There are no commonly accepted guidelines for the implementation of the principle. For instance, in spite of the *Communication on the Precautionary Principle* (2000),<sup>75</sup> which was introduced by the Commission of the European Communities in order to standardise the use of the principle, the adopted national precautionary policies within the EU have varied widely.<sup>76</sup> It should be emphasised, however, that the above-mentioned problems do not imply the abandonment of the precautionary principle (in all its forms). At best, they show that particular understandings of the principle are theoretically implausible and/or practically unworkable, and that certain modes of implementation should not be used. Hence, in the absence of further qualifications, the normative stance that the precautionary principle should be implemented in the risk governance of modern agri-biotech is untenable.

#### ***4.2 The Precautionary Principle Should not be Implemented in the Risk Governance of Modern Agri-Biotechnology***

Despite widespread support, the precautionary principle and its inclusion in modern agri-biotech risk governance have been subjected to substantial criticism. A number of noted scholars have attacked the principle.<sup>77</sup> Furthermore, the United States (US) has not accepted the principle as an official basis for its risk regulation, and the US has reproached the EU for imposing illicit trade barriers in the name of precaution. A common but oversimplified transatlantic antithesis states that, whilst the EU endorses the precautionary principle, the US opposes it.<sup>78</sup>

Arguments against the implementation of the precautionary principle in modern agri-biotech risk governance may be divided into three classes. First, it has been claimed that the precautionary principle is in itself flawed, and that the principle cannot thus be invoked as a basis for societal decisions. It follows that the precautionary principle should not be employed in biotechnology risk decision-making either. The precautionary principle has, for instance, been criticised for being

vague or ambiguous (i.e. for its alleged inability to provide concrete guidance in decision-making).<sup>79</sup> Moreover, the principle has been claimed to be unacceptably extreme (or absolute) in nature, and has thus been rejected as an unjustified basis for societal decision-making.<sup>80</sup>

The second class of arguments does not imply a commitment to the general (un)acceptability of the precautionary principle, but simply states that the principle should not be employed in agri-biotech risk governance. It has been argued, for instance, that the invoked precautionary policies – if implemented in practice – would lead to highly undesirable effects. According to Indur M. Goklany, “limiting GM crops [based upon the precautionary principle] will, by limiting the rate at which food production can expand, almost certainly increase death and disease, particularly among the world’s poor”.<sup>81</sup> Third, somebody might acknowledge the precautionary principle as a valid basis for certain risk decisions (or more generally for specific regulatory frameworks), and at the same time hold that the principle should not be applied in the context of modern agri-biotechnology. This stance may be premised upon a belief that the existing regulatory framework – without any additional or independent argument from precaution – forms a sufficient basis for agri-biotech risk governance.

*Problems.* The normative standpoint that the precautionary principle should not be implemented in the risk governance of modern agri-biotechnology also contains a number of problems. First, the proposed arguments against the precautionary principle are certainly valid for some (extreme) understandings of the principle, but the core propositions of precaution are hard to dispute. There are interpretations of the precautionary principle which no rational person would reject. For instance, the principle may take the following form: if there is an identified risk of environmental catastrophe with rigorous but not conclusive scientific evidence, then cost-effective and proportional precautionary measures are justified. Second, because there are commonly accepted reasons to take precautions in general, the burden of proof seems to lie with those who reject the inclusion of the precautionary principle into biotech risk governance. It can be claimed that the opponents should show why the context of biotechnology differs from other environmental and health protection where certain forms of the precautionary principle are well-founded. In the absence of such an argument, it seems safe to assume the opposite (i.e. the lack of such a difference). In sum, not only the proponents but also the antagonists of the precautionary principle (in the context of modern agri-biotech) need to specify their claims.

## 5 Discussion

The preceding analysis suggests that certain interpretations of the precautionary principle provide a well-founded basis for the risk governance of modern agri-biotechnology. Some of the presented risk arguments which refer to disputed or uncertain threats are credible. Moreover, it follows that subsequent constructive

discussion can concern only the middle stances between the positions explicated above. Consequently, protagonists should shift the debate from the one about “yes” and “no” stances into ones about the theoretical credibility and ethical justifiability of specific understandings of the principle.

This is not to claim that there has been no discussion on specific interpretations of the precautionary principle, however. There are such attempts.<sup>82</sup> Yet I want to point out that the current conceptual framework which has been employed to explicate and to evaluate different understandings of the precautionary principle includes serious flaws. In particular, the use of the distinction between the strong and weak interpretation of the precautionary principle (henceforth, the traditional distinction) is problematic. This basic distinction is repeatedly employed in academic literature related to the precautionary principle and elsewhere.<sup>83</sup> In practice, the traditional distinction means that different formulations (or definitions) of the precautionary principle (e.g. in official documents) are subsumed under two interpretations, and thereafter the strong and weak form are evaluated independently.<sup>84</sup>

Despite its established role, the traditional distinction cannot provide a useful tool for the rational evaluation of specific understandings of the precautionary principle. There are at least three reasons for this. First, the distinction has been employed in various ways. More precisely, the distinction is made on the basis of different (and sometimes even several) criteria instead of one and the same or generally agreed ones, as is usually presumed. Whilst certain authors consider the placing of the burden of proof as the decisive criterion between the interpretations,<sup>85</sup> others distinguish the weak and strong form by referring to the status of cost-benefit analysis.<sup>86</sup> The normative status of precautionary response has also been used as the criterion between the interpretations by some.<sup>87</sup> Second, the traditional distinction is not an exhaustive classification, i.e. it does not cover all readings of the precautionary principle. As an example of this, certain authors have argued that (the implementation of) the precautionary principle should affect the way in which risk assessment is framed and conducted, and thus the principle functions not only as a risk management tool/principle (as is often thought).<sup>88</sup> Notions such as “precautionary appraisal”<sup>89</sup> and “precautionary assessment”<sup>90</sup> reflect this kind of claim. Whether this reading of the precautionary principle fits into (any of the above-mentioned) strong or weak interpretations remains unclear. In sum, as a classification, the traditional distinction is neither exclusive nor exhaustive. Thirdly, the distinction is semantically misleading, that is, not all the strong interpretations are actually especially strong (i.e. more stringent within the two interpretations or influential in domestic and international policy), nor are weak ones especially weak (i.e. less stringent or insignificant).<sup>91</sup>

To conclude, the wide range of different understandings of the precautionary principle cannot be captured by simple classifications such as the traditional distinction. The specific interpretations of the principle (*viz.* the middle positions) may only be correctly evaluated one by one and in relation to the relevant regulatory context(s). Although serious academic efforts have already been dedicated to this task, much of the work seems to be undone.

The above discussion serves democratic ideals<sup>92</sup> in several respects. First, it aims to enable well-grounded decision-making practices in the context of modern biotechnology risk governance by questioning the usefulness of simple stances and classifications founded upon different understandings of the precautionary principle. Second, by highlighting risk issues which are currently uncertain and/or in dispute, and by explicating the precautionary principle upon which several policy decisions have been based, the transparency of agri-biotech decision-making is increased. The paper also contributes to the realisation of citizens' right to adequate, non-technical information concerning the issue. Lastly, a framework for non-specialists to form reasoned beliefs and attitudes towards both the risks of modern agri-biotech and their governance is provided.<sup>93</sup>

## Notes

<sup>1</sup> See e.g. CEC (2000).

<sup>2</sup> See e.g. FEC (2003).

<sup>3</sup> See e.g. Myhr & Traavik (2003).

<sup>4</sup> See e.g. Greenpeace.

<sup>5</sup> See e.g. Clark & Lehman (2001).

<sup>6</sup> We may lack factual and/or non-factual knowledge. When risk arguments are invoked, the lack of knowledge is more concentrated on the factual side – in particular on the predictive side – rather than on the evaluative and/or prescriptive side. Whilst the former is about our ability to make sound and accurate predictions (e.g. to assign the magnitude and probability of a risk in quantitative terms), the latter is concerned with the well-founded determination of thresholds (e.g. choosing the acceptable level of risk).

<sup>7</sup> See e.g. Streiffer & Hedemann (2005).

<sup>8</sup> The “playing God” argument (as well as several other categorical arguments) is commonly regarded as highly problematic or unsound, however. Sometimes the distinction between consequentialist and categorical arguments is made slightly differently, i.e. in terms of extrinsic and intrinsic concerns.

<sup>9</sup> See e.g. Levidow et al. (2005).

<sup>10</sup> *Ennaltavarautumisen periaate* (in Finnish), *försiktighetsprincip* (in Swedish), *Vorsorgeprinzip* (in German), *principe de précaution* (in French), *principio de precaución* (in Spanish). In English-language literature and official documents, the principle is also referred with the terms “precaution”, “the principle of precaution” and “the precautionary approach”. In this paper, I employ the phrase “the precautionary principle” as a uniting term for these expressions. For a discussion on the terminology, see e.g. Trouwborst (2002).

<sup>11</sup> Perhaps not surprisingly, much of the discussion has unfortunately been interest-driven or otherwise ideologically biased.

<sup>12</sup> Thus, the paper furthers the objectives of (genetic) democracy (see e.g. Siipi, *supra*).

<sup>13</sup> For an analysis of different risk concepts, see Renn 1992; see also Stirling (2004).

<sup>14</sup> See e.g. Shrader-Frechette (1985).

<sup>15</sup> However, it should be borne in mind that human action may contribute to several natural catastrophes. Global climate change provides an example in which the categories have become blurred.

<sup>16</sup> See e.g. Shrader-Frechette (1985).

<sup>17</sup> See e.g. Stirling (2002).

<sup>18</sup> Although the discussion has mostly been concerned with the risks related to agri-biotechnology development and its commercial use, the total risks include not only the introduction and use of these technologies but also the non-use of them (see e.g. Goklany (2001), 29–56, esp. 47–55).

- <sup>19</sup> For a review on the relevant peer-reviewed articles, see e.g. Weaver & Sean (2005).
- <sup>20</sup> See e.g. Myhr & Traavik (2003).
- <sup>21</sup> See e.g. Snow et al. (2005), 377.
- <sup>22</sup> See e.g. Wolfenbarger & Phifer (2000); Welsh & Ervin 2006.
- <sup>23</sup> Domingo (2000); Weaver & Sean (2005); see also Clark & Lehman (2001).
- <sup>24</sup> That is, non-GM foods.
- <sup>25</sup> See e.g. Netherwood et al. (2004).
- <sup>26</sup> These markers provide a tool for recognising whether a new gene has been successfully incorporated into a plant cell.
- <sup>27</sup> As a result of biological conjugation, random mutations in replication and selection.
- <sup>28</sup> See e.g. Perreten et al. (1997).
- <sup>29</sup> See e.g. Spök et al. (2005), 153.
- <sup>30</sup> See e.g. Martin (1997).
- <sup>31</sup> See e.g. Morris (2000).
- <sup>32</sup> See e.g. Hansson (1997).
- <sup>33</sup> First, do no harm.
- <sup>34</sup> See e.g. Graham & John (2002).
- <sup>35</sup> For a discussion, see e.g. Boehmer-Christiansen (1994).
- <sup>36</sup> Preamble, Para. 7.
- <sup>37</sup> It might also be argued that the principle was endorsed in the *World Charter for Nature*, which was adopted by the United Nations (UN) General Assembly in 1982. However, the term “the precautionary principle” (or other equivalent notions) is not explicitly mentioned.
- <sup>38</sup> The third substantive proposition does not determine the required level of scientific understanding at which taking precautions is warranted. This has resulted in disagreements. While most authors consider some kind of scientific evidence for an identified threat necessary, others claim that the principle can be applied on the basis of purely hypothetical threats (see e.g. Manson 2002, 270–274).
- <sup>39</sup> See e.g. Trouwborst (2002).
- <sup>40</sup> See e.g. Trouwborst (2002).
- <sup>41</sup> See e.g. Sandin (1999).
- <sup>42</sup> UNCED (1992), Principle 15.
- <sup>43</sup> See e.g. Manson (2002); VanderZwaag (2002).
- <sup>44</sup> See e.g. CPB (2000).
- <sup>45</sup> Wingspread 1998.
- <sup>46</sup> It is obvious that these two standard formulations of the precautionary principle differ. The former only says that uncertainty shall (should) not be used as a reason not to take cost-effective precautionary measures, whilst the latter states an obligation to take precautions with no reference to cost-effectiveness. Furthermore, the *Wingspread Statement* also states that the burden of proof should be shifted from the public (regulators and non-governmental organisations [NGOs]) to industry (scientific community etc.). Lastly, in the *Rio Declaration* the term “the precautionary approach” is employed, whereas the *Wingspread Statement* mentions the notion “the precautionary principle”.
- <sup>47</sup> See e.g. Turner & Hartzell (2004), 451.
- <sup>48</sup> As explicated by Per Sandin (1999), the formulations of the precautionary principle often differ with regard to the normative status of the precautionary response. For example, the application of precautionary measures may be stated as justified or obligatory (see also Cameron & Wade-Gery 1995).
- <sup>49</sup> See e.g. Nollkaemper (1996).
- <sup>50</sup> See e.g. UNCED (1992), Principle 15.
- <sup>51</sup> The chosen level of protection is often defined in general and qualitative terms, however. The EC Treaty, for instance, states that the “[c]ommunity policy on the environment shall aim at high level of protection” (1992, Article 174). Obviously, this definition and its equivalents leave much space for discretion.
- <sup>52</sup> If the probability of a threat can be assigned, the precautionary principle cannot be applied. Some other principle (e.g. the principle of preventative action) should be applied in these cases.

- <sup>53</sup> For a detailed discussion on different risk decision-making situations, see e.g. Stirling (2002).
- <sup>54</sup> As an example of the precautionary risk assessment methodologies, see e.g. Tickner (2003). For an analysis of the implemented (narrow and broad) precautionary policies within the EU, see e.g. Levidow et al. (2005).
- <sup>55</sup> See e.g. EEA (2001); FEC (2003); Myhr & Traavik (2003).
- <sup>56</sup> An interesting example of the latter can be found in Austrian biotechnology policies. The so-called Austrian standard of genetically modified organism (GMO) risk assessment goes beyond the strict scientific understanding of risk, and it can thus be considered precautionary in nature (Torgersen & Seifert 2000).
- <sup>57</sup> See e.g. 2001/18/EC; CEC (2000).
- <sup>58</sup> *Directive 2001/18/EC*, which is concerned with the deliberate release and placing on the market of genetically modified organisms, mentions the principle several times. Indeed, this directive could be described as creating a precautionary risk governance framework (see e.g. Schomberg 2006).
- <sup>59</sup> See e.g. CPB (2000).
- <sup>60</sup> Article 174 (2) of the Treaty Establishing the European Community. (The other mentioned principles are the principle of preventative action, the polluter pays principle, and the source principle.) See also the Commission's *Communication on the Precautionary Principle* (CEC 2000).
- <sup>61</sup> See e.g. EEA (2001).
- <sup>62</sup> Moreover, taking absolutely no precaution would be immoral from the ethical point of view, and may be irrational from the decision-theory point of view. Lastly, our willingness to be subjected to risks seems to be in inverse proportion to the level of well-being and prosperity.
- <sup>63</sup> See e.g. Marchant (2001), 151.
- <sup>64</sup> See e.g. Weaver & Sean (2005), 157.
- <sup>65</sup> See e.g. ISAAA (2005).
- <sup>66</sup> See e.g. Domingo (2000); Weaver & Sean (2005).
- <sup>67</sup> See e.g. Wolfenbarger & Phifer (2000); Welsh & Ervin (2006).
- <sup>68</sup> See e.g. Eurobarometers 58.0 and 64.3.
- <sup>69</sup> Although Europeans have become more optimistic concerning biotechnology in general, GM food is still "widely seen as not being useful, as morally unacceptable, and as risk for society" (*Eurobarometer* 64.3., 13–14,28).
- <sup>70</sup> See e.g. Ahteensuu (2007).
- <sup>71</sup> See e.g. Nollkaemper (1996); Ahteensuu (2007).
- <sup>72</sup> See e.g. Matthee & Vermersch (2000), 69.
- <sup>73</sup> See e.g. Morris (2000).
- <sup>74</sup> See e.g. VanderZwaag (2002).
- <sup>75</sup> See e.g. CEC (2000).
- <sup>76</sup> See e.g. Levidow et al. (2005).
- <sup>77</sup> See e.g. Holm & Harris (1999); Morris (2000); Starr (2003); Wildavsky (1996).
- <sup>78</sup> See e.g. Wiener & Jonathan (2002).
- <sup>79</sup> See e.g. Bodansky (1991); Marchant (2001); Turner & Hartzell (2004).
- <sup>80</sup> See e.g. Sunstein (2005); for a discussion, see e.g. Nollkaemper (1996).
- <sup>81</sup> Goklany (2001), 47,55–56. To be fair, Goklany's argument is more complicated than this quotation indicates. In his view, the precautionary principle, when properly applied, implies substantially different policies than the typically sought ones which are based upon a selective and biased invocation of the principle.
- <sup>82</sup> See e.g. Manson (2002), 270–274; Turner & Hartzell (2004).
- <sup>83</sup> See e.g. Foster et al. (2000); ECNH (2003).
- <sup>84</sup> See e.g. Morris (2000); Soule (2002).
- <sup>85</sup> See e.g. Wiener & Jonathan (2002); Manson (1999).
- <sup>86</sup> See e.g. Myhr & Traavik (2003); Soule (2002).
- <sup>87</sup> See e.g. Godard (1997).
- <sup>88</sup> Risk assessment and risk management are parts of scientific risk analysis which also includes risk communication. Risk assessment, as commonly characterised, is a process based on science in which knowledge about hazards is produced. It consists of a sequence of phases. Environmental and health risk

assessment includes (1) the identification of biological, chemical and physical agents which may cause adverse effects to human and animal health, and to the environment; (2) the characterisation of adverse effects which are associated with the identified agents; (3) the determination of the relationship between exposure to the identified agents and the severity and/or frequency of the associated adverse effects, and the evaluation of the likely intake of the agents; and (4) the estimation of the probability of occurrence and the severity of the adverse effects, and the evaluation of uncertainties which are identified during the assessment process. (See e.g. NRC 1983.) Risk management, in turn, consists of decision-making and action in which the characterised risks are governed. More precisely, it is a process of (1) evaluating and selecting between policy alternatives (i.e. regulatory actions and inactions) in the light of the results of risk assessment, and of (2) implementing the chosen regulatory actions. In addition to risk assessment results, risk management includes a consideration of social factors (such as political, technical and economic factors, and the attitudes of the general public). Finally, risk communication may briefly be described as the interactive exchange of information and opinions throughout the risk analysis process among risk assessors, risk managers, stakeholders and laymen. Two-way communication between experts and the general public is presumed. Specialists should provide a non-technical explanation of risk assessment findings and of the basis of risk management decisions.

<sup>89</sup> See e.g. Klinke et al. (2006).

<sup>90</sup> See e.g. Tickner (2003).

<sup>91</sup> The use of the plural form is justified on the basis of the argument from ambiguity. I have elaborated the three arguments against the use of the traditional distinction in length elsewhere (see e.g. Ahteensuu 2006; 2007).

<sup>92</sup> See Siipi, *supra*.

<sup>93</sup> I wish to thank Juha Rääkkä, Veikko Launis, Helena Siipi, Anne Ingeborg Myhr, Huei-Chih Niu and the participants of the “Turku Workshop on Genetic Democracy” (Turku, Finland, 21st–22nd August 2006) for helpful comments on an earlier draft of this paper.

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# Population Databanks and Democracy in Light of the Icelandic Experience

Vilhjálmur Árnason and Stefán Hjörleifsson

## 1 Introduction

In this paper we will discuss issues relating to democracy in light of the Icelandic experience of the databank resource of deCODE genetics. First, we briefly outline the main ideas about democracy that are the backbone of our analysis. Second, we analyze the procedure and ideas that dominated the (now aborted) plan of setting up the Icelandic Health Sector Database. We argue that, although backed by both popular and parliamentary following, there were serious flaws in the procedure from a democratic perspective. The dominant interests in securing privacy and material gain overrode the issues of agency and public dialogue. This mainly concerns the phase of establishing a population databank (where community consent is most important). Finally, we will discuss the relationship between issues of consent for population database research and democracy. We argue that different types of consent imply different visions of the citizen and only a dynamic ongoing consent respects the citizens as active and reflective beings. This mainly concerns the research phase of population databanking (where individual consent is most important).

## 2 Democracy

Two basic functions of democracy are relevant in the discussion of the regulation and implementation of genetic policies: Democracy is both an institutional framework which secures people's rights and a method for political decision making. From the perspective of democracy as an institutional framework, the main function of democracy is to protect the public from the abuse of political or administrative power and from other powerful players on the social scene. The most important means of securing this function of democracy is the separation of the legislative, executive and judicial powers in democratic states, which is to ensure the checks

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V. Árnason

Department of Philosophy and Centre for Ethics, University of Iceland  
e-mail: vilhjarn@hi.is

and balances of powers, so as to protect liberties of the citizens. Furthermore, the independence of each of these powers from private actors on the market must be secured as far as possible, and the public media – the fourth power – play a crucial role in this regard. Since it has already been demonstrated how the Icelandic Health Sector database case was flawed from this perspective of democracy,<sup>1</sup> we will focus more on the other function of democracy in this paper.

As a method for political decision making, the predominant form of democracy has been representative government formed in the wake of popular elections. In this context it is helpful to draw upon a distinction between two models of democracy. On the first model, sometimes referred to as “aggregative” view of democracy, the emphasis is on the majority view as a set of preferences which needs to be transformed into public decisions. The elected representatives of the public make the major political decisions and take the consequences in next general elections. On this view, the legitimacy of political decisions stems from the facts that they are made by the elected politicians and that they are within the limits of the law. The political role of the public can thus be reduced to mere instances of voting where people express their more or less private preferences for the issues and the candidates. In effect, political action is seen in terms of market behaviour: “The democratic method is that institutional arrangement for arriving at political decisions in which individuals acquire the power to decide by means of a competitive struggle for the people’s votes”.<sup>2</sup>

The aggregate model is thus a “vote-centric” position that goes hand in hand with strategies which are best suited for “winning the game” of power politics.<sup>3</sup> Jon Elster writes about this view that it “embodies a confusion between the kind of behaviour that is appropriate in the market place and that which is appropriate in the forum”.<sup>4</sup> This idea of a democratic forum is central to the other model of democracy, sometimes referred to as a “deliberative model”. In the public forum people engage in deliberation about political matters in a way which is quite distinct from isolated and private expression of preferences. Most importantly it implies that in public dialogue people have an active chance and motivation to adopt a civic standpoint so they may reconsider their preferences in light of arguments about what best contributes to the general interests.

The focus in this “talk-centric” position is then no longer on the aggregation of preferences in the voting result but on the processes of public deliberation and opinion formation that precede voting and public decisions. This position on democracy thus looks not only at voting behaviour and politics in the narrow sense but also at the channels of discussion and will-formation in the public sphere. This takes seriously the idea that democracy is a form of decision making which is based on rational dialogue as well as strategic power struggle. In line with this view, democracy has been defined as the rule of a free dialogue: “An essential feature of democratic government . . . is that it is government through discussion, by persuasion instead of by force”.<sup>5</sup> In the recent literature, this is discussed under the heading of deliberative democracy.<sup>6</sup> Our subsequent analysis is influenced by these ideas.

One of the main spokesmen of deliberative democracy, Joshua Cohen, writes in the spirit of Habermas: “outcomes are democratically legitimate if and only if they could be the object of a free and reasoned agreement among equals”.<sup>7</sup> This

should not be understood as a realistic aim as much as a *critical idea* which can help identify the role of power, coercion and ignorance in social decision-making. The critical idea of freedom in public deliberation highlights that all stakeholders should have opportunity to make their concerns part of the agenda, and even to make the very rules of the debate a topic in itself.<sup>8</sup> Such a discussion will encourage people to think about which arguments might be valid to everyone and not only from the point of view of a particular interest. This critical idea can be used to distinguish claims based on narrow self-interests from those conducive to the general public interests.

### **3 Issues Relating to the Icelandic Health Sector Database Plan**

In 1998 deCODE genetics announced its plan for a national Health Sector Database (HSD) in Iceland, which was intended to become a crucial resource for the company's research in population genetics. This plan received great publicity in the small community of Iceland as well as internationally, and deCODE's HSD plan has been thoroughly documented and debated by different scholars.<sup>9</sup> The deCODE database research project has in many respects had a strong democratic backing from the Icelandic people. This backing has both come from the general public who have been most willing to participate in the company's research projects and maintained their support in surveys, and from the representatives of the people in the Icelandic parliament where the HSD bill was passed with a substantial majority. Moreover, an extensive public debate took place during the time of the controversy about the (now aborted) HSD, mainly in the years 1998–2001. The parliamentary debate was also extensive. The parliament's health committee solicited views from a great number of institutions and individuals about the matter.

In light of these facts about democratic backing of the case – popular following, parliamentary majority, institutional reviews and public debate – it has been argued<sup>10</sup> that the decision to pass the bill “was clearly the product of informed democratic consent”. This is a debatable claim. One reason is that quantitative facts about extensive debate and overwhelming majority opinion must not be confused with the qualitative notion of consent which implies an understanding of the issue consented to. According to a Gallup poll conducted a month before the law was passed, only 13% of the Icelandic population claimed to have a good grasp of the issue. The motivation of people to participate was based on altruistic hope and perhaps also on successive rhetoric<sup>11</sup> rather than reliable information.

Previous analysis of the Icelandic parliamentary debate and administrative handling of the HSD concludes that they failed on account of procedural as well as substantive criteria for informed democratic consent.<sup>12</sup> Although the HSD debate was abound with information, much of the debate was uninformed, misleading and prejudicial. The bill was rushed through parliament, and to a large extent the community debate took place after the bill was passed. Institutional and professional views were solicited but informed criticism was largely ignored. Many of the professional viewpoints were not seen as important by leading politicians who even

scorned criticism from scientists as “outsiders” opinions. Community consultation was minimal and was conducted by the prospective licensee. A prior, free, reasoned and informed public dialogue which is a necessary condition for community consent never took place.

The procedural requirements for informed democratic consent relate to the two functions of democracy described above. This administrative handling of the HSD case shows an intimate connection throughout the process between the executive power branch, especially in the ministry of health, and the company.<sup>13</sup> The role of the parliament was more reactive. The separation between the public and the private “players on the scene” which is a key factor in a well functioning democracy was lacking. One episode in this saga was the ousting of the National Bioethics Committee in August 1999.<sup>14</sup> A professionally formed committee where members were mostly nominated by scientific institutes was replaced by one where members are exclusively nominated by ministries. Although the committee has worked well in the last years and has not been misused by political power, the criticism is inevitably invoked that this action “weakened the independence of the National Bioethics Committee and brought it under direct control of the government”.<sup>15</sup>

The handling of the case by the political authorities showed many features of power politics which appeals to the backings of the majority but ignores the way in which the majority position is formed. While the handling of the HSD case would seem to be legitimate from the “aggregative” standpoint, it can be critically evaluated in light of deliberative democracy. From this viewpoint procedural aspects which facilitate or impede public deliberation come into focus. It has to be acknowledged, for example, that democratic discussions take time. This is especially so when new and complicated issues, which concern crucial interests of every citizen in ways which are far from clear at the outset, are dealt with for the first time. Democratic decisions should respect the deliberated will of the public as opposed to opinions based on insufficient information. The decision makers themselves should make an effort to base their decisions on relevant information and good arguments. The precondition for this is that political issues are well presented within the society and that the public has good access to relevant information and to arenas suitable for deliberation. Attempts must be made to engage the citizens in an informed dialogue, or at least make informed media analyses available to them.

The media are thus bound to play a major role in this public sphere. It is important to ask how public authorities and media facilitate public deliberation and how well grounded criticism is taken into account in the preparation of policy. Having followed the media discussion of human genetics in Iceland closely, it seems to us that the Icelandic public did not have good access to relevant perspectives on the HSD issue or to arenas suitable for deliberation. The media coverage of human genetics was dominated by different voices either “for” or “against” deCODE genetics, while substantial arguments and the desirability of available ends were only infrequently debated.

Moreover, the focus and information needed to establish deliberation and to enlighten debate about challenges raised by genetics have not been made available or established in Icelandic news media. With a few exceptions neither public

authorities, political organizations, religious institutions nor other stakeholders have successfully promoted or pursued deliberation about human genetics in the news media. Press announcements from deCODE and events organized by the company receive extensive coverage, and the narrative structure and framing provided by deCODE are accepted by Icelandic media. Information about the complexities of genetic technologies and contemporary debates about the merits of approaches within genetics for improving the human condition are inadequately conveyed. The preconditions for informed deliberation are thus not fulfilled, and genetic research is defined in a way which precludes certain concerns from entering the debate.<sup>16</sup>

Thus, it seems to us that in Icelandic news media, the ends of high-tech health-care, prestige and financial profit are tacitly assumed or even enthusiastically embraced and it is mostly taken for granted that commercial genetic and pharmaceutical research is the means of choice for pursuing these ends (the most notable exception is the often exaggerated critique of *Mannvernd*, the Association of Icelanders for Ethics of Science and Medicine, which in our opinion has contributed more to the polarization of the debate than to a principled discussion in the spirit of deliberative democracy). Critical questions are not pursued by journalists, and public initiatives taken by deCODE lead to broad and uniformly positive coverage.

#### **4 Consent and Visions of the Citizen**

From the very beginning, the dominating ideas in the Icelandic discussion concerning participants' interests were the prospective medical benefits on the one hand and data security on the other hand. The emphasis was mainly on two kinds of technical issues, a legal technicality about personal identifiability and coding techniques for storing the information.<sup>17</sup> Security of information of the kind that was to go into the Icelandic database is a crucial issue. Data are collected, stored and used for various research purposes and in this context the discussion of risk is often focused on privacy protection. This is clearly important from a moral point of view since personal data should not get into the hands of insurance companies, employers or others that could be motivated to use them for discriminatory purposes.

There is a reason to believe, however, that the extensive discussion about these matters precluded discussion of issues relating to active human agency, for example of consent and informed public debate. This is indicative of the trend to regard genetic data collections as major resources to be mined for the benefit of society without the interference of the participating individuals who should simply trust regulating institutions to take care of their interests. The interests of the participants are then mainly understood from the perspective of security and welfare which squares well with a picture of passive rather than active citizens. This perspective needs to be complemented with emphasis on factors that can increase public awareness of

population research and strengthen the conditions for their decisions and responsibility for participation in the research.

Arguments concerning the importance of individual consent are often met with statements to the effect that they put private interests above public interests and surely this is often the case. It seems to us, however, that there are important public interests at stake as well in maintaining the ethos of voluntary consent to participation in database research and that neglecting it may weaken a democratic society in the long run. In order to substantiate this claim we will briefly discuss the controversy about consent for population database research.

It is understandable that the question of consent for participation in database research has been in the limelight of discussions about genetic data collections. Population data collections are resources for genetic research and it is impossible to describe in detail the research that will be performed on the data at the time of collection. This leads to the following dilemma: Either data will be collected with restricted informed consent which emphasizes private interests but radically diminishes the flexibility of the researchers and the possible benefits of the research, or data will be collected with unrestricted open consent which maximizes research flexibility but can undermine the conditions for moral agency of the participants. The challenge is to show how this dilemma can be dealt with without risking either the possible human welfare benefits or the moral agency interests at stake.

Our analysis of the democratic flaws of the HSD procedure undermines the contention that it was a result of an informed democratic community consent. The democratic facts of popular following and extensive debate, were used as a basis of an argument that it is fair to collect medical data under the presumption of consent.<sup>18</sup> Admittedly, it can be argued that the national debate, though flawed, provides an important background for the decisions of competent adults to opt in or out of the database. Nevertheless, members of marginalised groups (e.g. mentally ill, poor, illiterate, children), the protection of whom should be the primary concern of research regulation, are likely to be exactly those people who have not participated in or even followed the national debate over this issue, however extensive and conspicuous that debate may have been. Moreover, as has been pointed out, “a community can approve a research project. It cannot legally or ethically require individual members of the community to participate”.<sup>19</sup> Although it is reasonable to argue that the community approval for the deCODE project was an important background for the parliament act on the HSD, it cannot be referred to generally as an argument for presumed consent of individuals.

The hardest critics of the deCODE project have demanded restricted informed consent. Restricted consent implies that participants will be informed prior to donating their samples or data for research about its objectives, risks, benefits and other traditional ingredients of informed consent. The main problem with restricted informed consent in this context is that it is unsuitable for multi-disease research on genetic collections. If data are collected for a specified research on the data and no research must be carried out on the data that was not specified in the consent form, then any research with new questions requires recontact with the participants. Participants find such continuous recontact annoying and experience has shown that

they are willing to give a wider consent and leave it up to the researchers and the regulatory committees to ensure that they are used for the benefit of science and society. Due to the nature of database research and the strict privacy procedures, this is not a risky research participation in the sense that it is likely to harm the participant.

Another objection could be based on the fact that what happens in reality is that while the objective of restricted consent is to maximize options for individual deliberation, detailed descriptions in scientific protocols are likely to overwhelm participants' intellectual capacity. The paradox is that the more information is provided, the less understanding is obtained and the consent procedure becomes a mere formality. In this way, opportunities for deliberation are actually lost and the interest in human agency is not well served.

It is understandable that researchers reject restricted individual consent for database research and prefer a version of open consent. By an open consent is meant here that participants agree that their data will be used for any future scientific research permitted by the regulatory institutions. The main emphasis is thus laid upon institutional trust and science ethics committees would evaluate the participants' interests and act (as surrogates) on their behalf. An unrestricted open consent, however, is risky in the sense that it does not sustain the conditions for moral agency. Open consent does not provide participants with the information necessary for them to make a meaningful choice, i.e. act in a voluntary way on a basic understanding of the matter.

In order to avoid these pitfalls of the restricted and the open consent, alternatives that are intended to strike a balance between the researchers' need for flexibility and the ethical demand for protection of participants' interests have been proposed.<sup>20</sup> The main thrust of these proposals, which have different emphasis, is that participants should be asked to authorize the use of their data for described health care research. They would be informed about the conditions for use of the data, such as how research on the data will be regulated, how they will be connected to other data, who will have access to the information and how privacy will be secured, and that they will only be used for described health care purposes. Participants would be informed that they and/or their proxies will be regularly informed about the research practice and that they can at any time withdraw data from the research.

Such an authorization or permission would both allow participants "to meaningfully act on their continuing interests in their health information"<sup>21</sup> and provide science ethics committees with a meaningful ground for determining further use of the information. Such further use is restricted to comparable research where members of science ethics committees can reasonably argue that the additional research would not have affected the participants' initial decision to participate. Such a policy would maintain the motivation for participants to reflect on their participation in research and to stay informed about how their data are used and for what purposes. An authorization policy would thus contribute to informed, reflective and responsible research participation that can underpin public trust in research practices. None of these would flow from an open consent policy for database research.

All these considerations are relevant for avoiding two of the most serious dangers of scientific research on humans, those of deception and coercion. The authorization proposal implies that individuals are offered “simple and realistic ways of checking that what they consent to is indeed what happens and what they do not consent to does not happen”.<sup>22</sup> If the latter happens, they can opt out. In addition to strengthening the basis for non-deception, this last point aims at securing the purpose of non-coercion, since it implies that participants need not continue research against their will. Only in that way can the interests associated with moral agency be secured and that, in the last analysis, is crucial in any evaluation of advantages to human society.<sup>23</sup>

This discussion of three types of consent – restricted consent, open consent, and dynamic authorization for the conditions of use – can be translated into three different visions of the citizen in democratic society. The emphasis on the need for restricted individual informed consent squares well with an atomistic view of the citizen where individual rights would trump any considerations about collective advantages. It is interesting to note how this appeal to individual rights has been used strategically by activist opponents of commercialized database research who do not generally adhere to individualistic politics. This has, for example, been apparent in the requirement of the spokesmen of *Mannvernd* to stick to restricted informed consent as a human right.<sup>24</sup>

The emphasis on an open and unrestricted consent, which relies on trust in regulatory institutions and the hope for medical benefits, has both communitarian and utilitarian flavours, depending on how the arguments are formulated. A utilitarian argument could be that public interests are best served by mining the data resource in an efficient way for drug development and other medical benefits. The Icelandic parliamentary discussion clearly had such a utilitarian tone which was increased by reference to additional advantages, such as increased employment opportunities for young scientists. There was also a strong appeal in the discussion to the national genome and medical records as social resources that should be exploited for the common good. In communitarian language these can be called goods that we can only create in common and not in atomistic isolation.<sup>25</sup> From this viewpoint, the emphasis should be on the duties of participants to contribute to progress in medicine and science as well as on their rights to be protected. It is in line with this position to transfer the reflection on genetic research from the participants themselves to the regulatory institutions. In this way, the pressure for an unrestricted open consent runs the risk of undermining the ethos of meaningful voluntary consent in research which in the long run could be detrimental to the public trust in science and hence be bad for society. Trust is a major asset that must not be misused.

But these otherwise contrary positions regarding database consent – unrestricted consent for facilitating research vs. restricted consent for securing options for individual deliberation – share a more important underlying presumption concerning the scientific citizenry that is being created. Those who argue for an unrestricted consent find it crucial to mine the resource and reap the benefits while those who favour restricted individual consent (which in fact becomes a mere formality for most people) are satisfied with obtaining a consent from otherwise passive participants. Each

in their own way effectively thwart realistic options for the participants to reflect upon their participation and thus undermine scientific literacy and awareness of the population.

It is, however, integral to the authorization approach to consent that participants will be encouraged by regulatory institutions to follow the research practices. This provides conditions for an active opt-out clause which is likely to create more informed and critically aware citizens and is also conducive to informed trust. This position thus enables *scientific citizenship* because it emphasizes the creation of conditions for citizens to reflect on their participation in scientific research rather than being merely passive part of a resource. This calls for scientific education, preparing people for active participation in a society where biological research and biotechnology play an increasing role. Another important factor would be strengthening the media by professional science journalists with insight into scientific discourse and ability to present it to the public.

The notion of scientific citizenship is used here in a normative, critical way and not only as a descriptive term, as tends to be prevailing in important sociological analysis of biological citizenship, where all kinds of reactions of the citizens to the new genetics are regarded as examples of biological citizenship or “different citizenship practices” in response to “new technologies which intervene on the body”.<sup>26</sup> Our use of the term “scientific citizenship” is more in the spirit of theories of democratic citizenship which tell us how “active, informed, and responsible citizens debate and resolve their disagreements”.<sup>27</sup> This normative idea of scientific citizenship can be criticized from the viewpoint of “neutrality of rationale” for scientific policies.<sup>28</sup> However, it must be emphasized that the idea is mainly to offer participants the *chance* to be active and reflective and not to *require* that they be so. It is an important part of liberalism that people are not passively subjected to policies and that they are provided with the opportunity to exercise their status as free and responsible agents. The conditions for this must not be reduced to information provided when consent is obtained but need to be seen in a larger cultural context.

As was apparent in our description of deliberative democracy above, one of its main ideas is rational will formation based on informed dialogue. This implies a creative tension between input from expert sources and lay positions in public deliberation. It is an integral part of the deliberative position, that this tension must not be cheaply released either by placing the emphasis exclusively on expert knowledge or by mere appeal to “what people want”; and in some instances deliberation may include calling the sharp distinction between impartial expertise and subjective lay preferences into question. The idea of scientific citizenship can be understood as an attempt to find an appropriate balance between the factors of will and knowledge. The objective is to create more informed or educated citizens who do not have to rely exclusively on expert knowledge but can use it in their deliberations about research participation. This, of course, is not something that can be easily realized but it is an important vision to guide our attempts in shaping citizens’ awareness in future society.

In order to implement the dynamic authorization approach to participation in large scale database research and promote scientific citizenship, multiple and diverse

experiments would probably be needed. As in Irwin's study of public consultation processes in the UK,<sup>29</sup> it seems that different practical arrangements must be tried out and scrutinized for the way they define and shape scientific citizenship. Different stakeholder interests would have to be balanced and conceptual inertia fought against. On the one hand, for example, if science ethics committees were to regulate the processes of dynamic authorization, they might be prone to propagating criteria of informed, restricted consent. On the other hand, researchers and commercial stakeholders such as deCODE would probably tend to frame the deliberative part of the authorization process as a one-way provision of scientific information to the public. Probably, therefore, new institutional solutions would be needed. As one step towards envisaging such solutions we suggest that those who fund genetic database research and other large scale biotechnology research in Iceland should also be required to fund an independent agency that would have the promotion of broad debate about research practices as its purpose.

## 5 Conclusion

In this paper we have drawn upon the ideas of deliberative democracy to evaluate the Icelandic databank project in Iceland. We argued that both the political handling and the extensive public discussion of human genetics fall short of normative criteria of democratic debate or deliberation. Furthermore, we tried to show how the debate about consent implies positions which are problematic from a deliberative democratic viewpoint. It has understood the interests of participants from an overly narrow perspective and reduced public interest to material benefits, neglecting interests in human agency. We have argued that alternative proposals about broader dynamic consent with an active opt-out clause can contribute to an informed scientific citizenship that is important for democracy in contemporary information society. This democratic vision has been lost in the mainstream discussion of mining the population for maximum gain, providing that the data are securely protected. We maintain that there is a need to place the issue of database consent in a wider context of biopolitics where public deliberation is no less important than security and medical benefits, and we suggest that governance experiments and novel institutional arrangements may be needed if public deliberation and policy processes are to gain sufficient independence and weight *vis à vis* genetic database research.

## Notes

- <sup>1</sup> Árnason & Árnason (2004).
- <sup>2</sup> Schumpeter (1950: 269).
- <sup>3</sup> Kymlicka (2002: 290).
- <sup>4</sup> Bohman & Rehg (1997: 10).

- <sup>5</sup> Raphael (1970: 150).
- <sup>6</sup> Cf. Benhabib (1996), Bohman & Rehg (1997) and Dryzek (2000).
- <sup>7</sup> Bohman & Rehg (1997: 10).
- <sup>8</sup> Benhabib (1996: 79).
- <sup>9</sup> Who Owns Our Genes? (2000), Chadwick (1991), Greely (2000), Rose (2001) and Árnason (2004).
- <sup>10</sup> Pálsson & Rabinow (1999).
- <sup>11</sup> Árnason & Simpson (2003).
- <sup>12</sup> Árnason & Árnason (2004: 174–5).
- <sup>13</sup> This is substantiated with examples in Árnason & Árnason (2004).
- <sup>14</sup> Cf. Abbot (1999).
- <sup>15</sup> Zoëga & Anderson in *Who Owns Our Genes* (2000: 42).
- <sup>16</sup> In the case of the UK Biobank, a similar failure to identify and engage with critical issues has been documented by Petersen (2005) and Hoeyer & Tutton (2005). Hjörleifsson, Strand & Schei (2005) provide an extensive catalogue of concerns about genetic research and the ensuing technologies among deCODE’s researchers themselves as well as among research participants.
- <sup>17</sup> Árnason (2004).
- <sup>18</sup> Gulcher & Stefánsson (2000).
- <sup>19</sup> Annas (2000).
- <sup>20</sup> Greely (1999); Arnason (2003); Caulfield, Upshur & Daar (2003), and Kaye (2004). An interesting solution of the Icelandic National Bioethics committee is not to choose among a restricted and more open consent, but rather to provide a “menu” of three types of consent which the participants themselves can choose between. Most opt for the widest one, although this is not an open consent in the sense we used above.
- <sup>21</sup> Caulfield, Upshur & Daar (2003: 3).
- <sup>22</sup> O’Neill (2001: 32).
- <sup>23</sup> See on this point Kristinsson (2007).
- <sup>24</sup> Cf. the website: [www.mannvernd.is/english/](http://www.mannvernd.is/english/)
- <sup>25</sup> Cf. Sandel (1982: 183).
- <sup>26</sup> Rose (2005).
- <sup>27</sup> Kymlicka (2002: 286).
- <sup>28</sup> Kristinsson (2006).
- <sup>29</sup> Irwin (2001).

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# Equality and Community in Public Deliberation: Genetic Democracy in Taiwan

Terence Hua Tai and Wen-Tsong Chiou

## 1 Introduction

In 2004, the Science and Technology Advisory Group in the Executive Branch of Taiwan's government made a policy recommendation, which was subsequently adopted, that Taiwan should strive to become an "island of biomedical technology" if it is to seek a better prospect for economic growth in the near future. Three infrastructure objectives were put forward together with this national goal: (1) to digitalize all health records kept by the Bureau of National Health Insurance in Taiwan, (2) to institute a sound regulatory framework for clinical research, and (3) to establish a Taiwan Biobank.<sup>1</sup> These are interconnected and definitely challenging tasks. In order to pave the way for accomplishing the third objective in particular, the National Science Council of Taiwan requested the Institute of Biomedical Sciences (IBMS) at Academia Sinica, the highest-ranking academic institution for basic research in the nation, to draft a blueprint of the envisaged large-scale human genetic repository and to conduct pilot study on its feasibility. Well aware of the ethical, legal and social issues (ELSI) that might be involved in this endeavor, the IBMS invited a team of scholars, who had been conducting ELSI-related research funded by the National Science Council, to collaborate with biomedical experts in order to work out a regulatory framework for the Taiwan Biobank. Such a framework has been duly recognized as essential to the success of the Taiwan Biobank Project, which, once officially launched, is obviously in need of long-term public trust and support.

However, the pilot project undertaken by the IBMS since 2005 has repeatedly encountered stern criticisms in the national news media. It is noteworthy that not only are these criticisms directed to issues about protection of genetic privacy, but they also call for public deliberation on the acceptability of such a large-scale genetic database. During the last decade, Taiwan has been undergoing a rapid process of democratization, and nowadays a strong conviction can easily be detected in

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T.H. Tai

Professor and Chair in the Department of Philosophy at the National Chengchi University, Taiwan  
e-mail: ttai@gate.sinica.edu.tw

public discourse that such basic values in a pluralistic democratic society as personal autonomy and social justice should be accorded moral weight to be balanced against the familiar appeal to national prosperity or general welfare. This prevailing ethos in Taiwan has added attractiveness to the claim that the Taiwan Biobank Project should be scrutinized through public deliberation, especially in view of the fact that the Project will consume a large amount of public funds and require the willingness and long-term participation of a great number of ordinary citizens. How such deliberation is supposed to be carried out and, more importantly, how the requisite deliberative process is to be organized in the first place are admittedly difficult questions (the solution to which may itself require consensus). Nevertheless, it seems safe to say beforehand that since indigenous peoples are one of the four populations targeted by the Taiwan Biobank, whether or not they, as a social group or community that has long suffered various sorts of inequalities, can *really* (not only formally) have an equal representation in the deliberative process in question may serve as a litmus test for the adequacy and trustworthiness of such a process.

As will be explained later in this chapter, a recent event in which members of an aboriginal tribe jointly requested withdrawal from a genetic research highlights the urgency of this question, and makes it even more complicated: representatives of the tribe argued not only that the procedure for individual informed consent had been poorly conducted, but also that, according to the Basic Laws of Indigenous Peoples promulgated just recently in 2005, researchers should have consulted the tribe so as to obtain tribal consent. This event made national headline news with a full-page report, and so far the tribe's claim about the necessity of prior tribal consent has not been questioned. Thus, it seems, a similar claim can also be made, by appealing to the Basic Law, that community consent of the indigenous peoples in Taiwan should be obtained through *some* form of public deliberation among them if the Taiwan Biobank Project is to include them as one of its target populations. If this is an acceptable claim, then in case the indigenous peoples decide through public deliberation to give their *dissent* to the Taiwan Biobank Project, this will amount to a veto over the right of their individual members to decide for themselves whether or not to participate in the Project. Such a consequence may sound unsettling to anyone who takes individual rights to be fundamental.

In this chapter, we will first describe how Taiwan has endeavored to move ahead toward establishing a large human genetic repository, the Taiwan Biobank, for research in the post-genomic era, and what ethical, legal and social issues have been raised by this project. Against this background, we will argue that, while it is necessary for the democratic legitimacy of the Taiwan Biobank that its ethics and governance framework be subjected to the scrutiny of a (suitably designed) public deliberative process, the requirement that community consent of indigenous peoples be obtained before their individual members can exercise their right to decide whether or not to participate does not have to vitiate the fundamental status of individual rights. On the contrary, such community consent may empower members of the indigenous communities, enabling individuals to exercise their rights more substantively than without prior consent of the long exploited, disadvantaged and vulnerable communities to which they belong.

But we will argue against the need for indiscriminate prior public consent concerning (what we call) internal arrangements of a biobanking project at the national level over individual consent. In our view, while public deliberation at this level must proceed against the background of certain institutions and public policies that must be accountably determined and put in place to regulate the Taiwan Biobank “from the outside,” the deliberation on internal arrangements needs only to yield reasoned judgments, pros and cons, that may be taken into account by individual citizens when they come to make their own decision as to whether the Taiwan Biobank Project is worthy of their trust and participation.

## 2 Design of the Taiwan Biobank

Taiwan Biobank is intended primarily to be a population-based human genetic repository for prospective cohort studies on the interaction between environmental and genetic factors in the etiology of various chronic diseases common in Taiwan such as cancers, cardiovascular diseases, diabetes, hepatitis, hepatocirrhosis, etc. It aims to collect and store blood samples and lifestyle information from 200,000 participants aged 40–70, with linkage to their health records kept by the Bureau of National Health Insurance. The target populations include: (1) people of Fu-kien, or Hoklo, descent (immigrants of the 19th century or earlier from mainland China); (2) people of Hakka descent (immigrants of the 19th century or earlier from the mainland); (3) the so-called “mainlanders,” a group name coined in the mid-20th century to refer to people who came to Taiwan when the nationalist government took refuge in the island in 1949 after its defeat by the Chinese communists; and finally, (4) indigenous peoples, the earliest inhabitants of Taiwan who were forced by later settlers over the last four centuries or so to retreat to mountainous areas and less developed eastern shores.

A survey conducted by the Council of Hakka Affairs in 2004 shows that when asked about one’s ethnic identity, with multiple choices allowed, 80 % of those interviewed regarded themselves as Hoklos, 22.4 % as Hakkas, 13.1 % as “mainlanders,” and 5.3 % as indigenes. While this may give a good idea of the relative sizes of different populations in Taiwan today, it also shows considerable intermixing among them. In order to establish a repository that is recognizably population-based, the plan for the Taiwan Biobank is to recruit participants in the following three locations: Miao-li county in northern Taiwan, where the majority residents are of Hakka descent; Jia-yi city in the south, a typical Hoklo area; and the Hua-lien county at the east coast, where the indigenous population is much larger than elsewhere in Taiwan. The mainlanders, though a minority in all three locations, are of a sufficient size in each location to be included as a target population in the Taiwan Biobank.

In view of the highly controversial nature of such a large-scale genetic database, Taiwan’s government decided in 2005 to explore its feasibility through an NSC-funded pilot project, to be carried out by the IBMS of Academia Sinica. The pilot project was aimed at recruiting 1,000 participants (in Jia-yi city) to evaluate the

rationality and reasonableness of protocol procedures to be used when the Taiwan Biobank Project gets officially under way. After the proposal of the pilot project went to the Research Ethics Committee of Academia Sinica for review, a conspicuous commentary appeared in a national newspaper *China Times* in January 2006, raising several important questions about confidentiality, informed consent and benefit sharing.<sup>2</sup> The author of the commentary demanded that the entire plan for Taiwan Biobank be made public and subjected to open debate. The commentary accused the IBMS of having been secretly taking some ethically dubious first steps toward establishing the Taiwan Biobank by collecting as many as 3,000 blood samples in the east coast. Such accusation proves to stem from misinformation, for, strictly speaking, no blood sample has ever been collected so far under the name of the Taiwan Biobank Project. While the commentary may have mistaken another, less-noticed genetic database project of the IBMS (which is equally in need of public scrutiny) for the Taiwan Biobank Project, it attests to the widespread distrust of genetic research enterprises.

### 3 Unfavorable Circumstances

It is unfortunate that the plan for a Taiwan Biobank was proposed under circumstances that made public trust difficult to attain. First of all, there have been high-profile incidents in which supposedly confidential personal information of credit-card holders was leaked to people who used the information to commit fraud. These incidents gave rise to heightened awareness on the part of the general public about the importance of privacy protection. At the same time, dissatisfaction with the government's capacities to protect personal privacy has also been on the rise. Failing to appreciate the extent of public distrust and scepticism, the Department of Health once intended to issue an all-embracing IC version of the national health insurance cards that carry both personal health records and other personal information, but eventually settled for a much truncated version because of strong opposition.<sup>3</sup> More recently, a newly passed law authorizing the Ministry of Internal Affairs to require citizens to leave fingerprints before getting their renewed national ID cards was soon declared unconstitutional by the Constitutional Court on the ground that the law infringed upon informational privacy.<sup>4</sup>

In the last two years, the Department of Health has begun to review and improve its regulations of research involving human subjects. Though never too late to make, this move is long overdue. The indigenes, in particular, have been persistent victims of a long history of exploitation in which researchers often went to tribal villages to covertly collect blood samples under the guise of "free health checks." A news report even quoted a villager as saying that in just one year he gave blood "eight" times—meaning, perhaps, "several" times in his native tongue—for "free health checks."<sup>5</sup> Moreover, the Bureau of Health Promotion has been offering indigenous elderly two physical examinations per year for free, but, lacking a sound monitoring procedure, this well-intentioned health policy has unfortunately made the examinees

vulnerable to surreptitious, unconsented extraction of more blood from them than is necessary for the proclaimed purpose.<sup>6</sup> Worse still, even today one still finds that the registration form of a major hospital in an east-coast county<sup>7</sup> requires indigenous patients to fill in tribal origins of their parents and grandparents—something that is absolutely unnecessary for diagnostic or therapeutic purposes.

City folks in Taiwan have not been free from worries about similar abuses befalling them. In 2005 the Consumers' Foundation of Taiwan pointed out in a press conference that “[p]atients have no obligation to act like ‘mice in the lab’ for physicians and researchers.” According to the Foundation, a physician at a prestigious military hospital in the capital city Taipei collected blood samples for research use without going through the informed consent procedure properly. It was alleged, with good reason we think, that the physician had failed to discern possible conflict between the role of a physician and that of a medical researcher, so that his (or her) patients might have signed what was actually the consent form for donating their blood samples, thinking that this was only for treatment of their illness.

Given such an atmosphere of distrust and suspicion, it seems safe to assume that the public tend to be concerned more with the protection of their basic rights than with the promotion of general welfare in health care through medical research. Thus, in January 2006, the *China Times* was keen enough to issue a full-page special report on ethical issues over the Taiwan Biobank Project shortly after the appearance of the critical commentary mentioned above. The *China Times* ran a provocative headline on the front page that day: “Academia Sinica Plans to Pry into People’s Privacy.”<sup>8</sup> The special report led to follow-up coverage by major TV news channels. Deliberating under this climate of public distrust, the Research Ethics Committee of Academia Sinica finally approved the pilot project on the feasibility of Taiwan Biobank, but only on the condition that there should be *no actual collection of blood samples* taking place at this early stage.

#### 4 Individual Consent is Not Enough

Critics of the Taiwan Biobank Project argue that individual consent to participation ought to be obtained by appeal to altruism, and through forthright account of possible risks and benefits not only to individual participants but also to family members and different social groups. Moreover, they argue for benefit sharing, and for some form of collective or social consent that is to be obtained through an appropriate deliberative process if the Taiwan Biobank Project is to proceed in any legitimate way.

This appeal to social consent raises important questions. Inevitably, public deliberation can only involve a *limited* number of (suitably selected) representatives. Suppose that the outcome of such deliberation is that the Taiwan Biobank Project is in the opinion of the deliberators *not* worthy of public trust, or even ethically flawed, and should therefore be rejected. This outcome will very likely influence public opinion and bring about strong opposition to the Project. But why should this outcome

be binding on those who did not participate in the deliberative process? Suppose that there are still some individuals in the society who disagree with the outcome of public deliberation and whose considered judgment is that they should, despite the outcome, be left free to decide on their own whether or not to participate in the Project—just as they should be left free to do so even if public deliberation results in unanimous consent to the Project. Can't these people give their individual consent to participate in the Taiwan Biobank Project *in spite of* the dissent, if any, arrived at through public deliberation? Does public deliberation carry enough moral weight to make an individual's decision to act contrary to its conclusion morally *unjustified*? If, after considering the case in an unobjectionably informed way, one decides to participate, then isn't it morally permissible for one to do so? What grounds can there be for conferring upon public deliberation a moral veto power over individual consent?

An answer to these questions seems to be suggested by Onora O'Neill's criticisms of individual informed consent as it has been traditionally understood. O'Neill first points out a problem—a "philosophical weakness," as she puts it—that she thinks is inherent in individual informed consent. Consent is a "propositional attitude" that is "referentially opaque": a propositional attitude is a mental state with propositional content, and it is "referentially opaque" just in case its content cannot be replaced by its logical equivalent or any of its implications without falsely attributing the resultant attitude to the subject of the original attitude.<sup>9</sup> For example, *belief* is a propositional attitude with referentially opaque content, for supposing that I believe Mark Twain is the author of *The Adventures of Huckleberry Finn*, then even though Mark Twain is actually the pseudonym of someone known as Samuel Clemens, you cannot validly infer that I also believe Samuel Clemens is the author of *The Adventures of Huckleberry Finn* (for I may be unaware that Mark Twain *is* Samuel Clemens). *Consent* is like belief in this respect. Even if I give my consent to a medical treatment on the basis of what is explicitly written in a consent form, I may be unable to comprehend all that is implied by the actual contents of the consent form, and it is possible that I would have, instead, *dissented* if I had known some of their implications.

The upshot is that it is hard to tell whether the consent I give to a medical treatment or research amounts to *informed* consent. Thus, even granted that informed consent is *sufficient* to justify administering a medical treatment to a patient or enlisting a human subject in a medical research, and that it is not necessary to inform an individual of *everything* about a medical treatment or clinical trial in order for his or her consent to participating in it to be valid, it is still hard to draw a clear line between when this sufficient condition is satisfied and when it is not. The situation may be further complicated when we move away from the clinical setting. As traditionally conceived, informed consent is given by an individual, and the consent procedure has been applied typically in the clinical setting. Many writers and international guidelines have now come to conclude that individual informed consent *alone* is not sufficient to justify the collection, storage and use of human biological samples in the setting of large-scale biobanking, targeted at populations. While *individual* informed consent may well be indispensable in this new context nonetheless, serving as what may be called "the lowest common denominator,"<sup>10</sup> it is now believed by some to be by itself *insufficient*: the so-called "public consent,"

at least in the increasingly important setting of large-scale biobanking, seems to be a necessary supplement.

Advocates of this idea include O'Neill, who introduces it when distinguishing between "seeking *public consent to systems* for collecting, storing, using and disclosing [personal genetic] data" and "seeking (a necessarily limited degree of) *individual consent to particular acts* of collecting, storing or disclosing data about individuals."<sup>11</sup> The difficulty caused by "referential opacity" in telling when an individual has really made an *informed* consent is aggravated by recent technological developments: "the merger of genetic and information technologies make it possible to assemble massive quantities of complex information *that defeat individuals' best efforts to grasp what is at stake*, or to give or withhold informed consent."<sup>12</sup> In O'Neill's view, a feasible way to overcome this difficulty is not to provide *more information* but, instead, to introduce "public consent" procedures aimed at examining the adequacy and trustworthiness of systems or institutions for the protection of personal genetic data from misuse or improper disclosure.

Before delving further into O'Neill's proposal, we need, first of all, to clarify two types of regulatory schemes and their decision-making mechanisms. On the one hand, there are existing regulatory arrangements related but *external* to a particular biobanking project. These may include, among others, governmental policies concerning the development of science and technology, regulations of research involving human subjects, legal protection of personal data in general, laws that ensure free public access to governmental information, and even the budgeting mechanism. On the other hand, there are regulatory arrangements *internal* to a particular biobanking project that include at least an ethics and governance framework congruent with the *external* arrangements and specific to the design of the proposed biobank. Since the *external* arrangements specify the minimal setting for the *internal* arrangements of a particular biobanking project, they may in some cases entirely foreclose a proposed biobanking project. For example, a law prohibiting data linkage among different databases would prohibit the establishment of any biobank that intends to link personal health records with genetic repository, and a governmental policy that disallows public money to be used to fund biobanking would make a costly project extremely difficult to carry out. While those *external* arrangements have long been the focal points of struggle among different stake-holder groups in the traditional political arena, and policy deliberation is especially needed for a publicly-funded biobanking project, we take it that by "seeking public consent to *systems* for collecting, storing, using and disclosing data" O'Neill means the latter, internal arrangements. For her, public consent to these arrangements is *prior* to individual informed consent to participation in the project that is to be internally regulated by them; in other words, only after a (suitably composed) deliberative body has given its public consent to arrangements internal to a biobanking project can the project be allowed to go about seeking individual informed consent from potential participants. To take issue with O'Neill's proposal, our following discussion will focus primarily on the role that different communities may play concerning the *internal* arrangements of a biobanking project.

## 5 Other Grounds for the Priority of Public Consent

O'Neill's claim for the priority of public consent is chiefly grounded on the fact that genetic and information technologies are working together to introduce new and ever-growing powers for processing "massive quantities of complex information" in ways that far surpass the cognitive capacities of ordinary people to comprehend what personal information is actually at stake and, for that matter, what can serve as trustworthy protection of their privacy. O'Neill is concerned, at bottom, about the adequacy of the protective means used by systems of information processing for research purposes to ensure an important value presumably held by all, i.e., *individual privacy*. So grounded, the claim does not seem to imply that the requisite deliberative process for the formation of public consent must incorporate equal representation of especially vulnerable communities in such a process. That is, *one possible way* to alleviate O'Neill's specific worries under discussion here seems to be for the deliberative process to involve no more than experts in the relevant fields together with some lay persons acting as representatives of the "general public" (rather than members of particular social groups). Moreover, if public deliberation grounded in this way results in *dissent* to a biobanking project, it seems likely to be considered *improperly* paternalistic by those who do not think that issues about the protection of privacy matter much: they may well insist that even if such deliberation can legitimately provide recommendations that tend to influence people's decision to give or withhold consent, it ought to refrain from pronouncing public dissent that deprives people of the opportunity to make such decision for themselves.

However, there may be grounds other than O'Neill's for the priority of "*public consent to systems* for collecting, storing, using and disclosing [genetic] data." For one thing, in the context of large-scale biobanking, interests involved and values concerned may pertain neither to *individual* citizens nor to their *privacy*. A variety of important interests of the communities implicated may be at stake. Thus, although samples collected and stored in a biobank will be encrypted, with personal identifiers removed, subsequent research using the samples and genetic information derived from them will often depend on the availability of group identities—such as ethnic, gender, and occupational identities—of sample sources. While such research holds promise for enormous improvements in medicine and public health, it also raises serious concern that publicized research results and their implications about the genetic and environmental factors in the etiology of diseases might foster stigmatization and unjust discrimination against vulnerable communities as a whole. In order to protect these communities from such unjust disadvantages, we cannot rely solely on individual informed consent, for interests of an individual (and their priorities) do not necessarily coincide with those of the community to which he or she belongs. As a matter of justice, public deliberation is needed to safeguard the latter interests. Grounded in this way, the relevant deliberative process will have to include representatives from communities whose interests are foreseeably put at risk by a biobanking project. But can this deliberative process be allowed to issue in

public consent or dissent that is not amenable to the kind of objection raised against O'Neill's proposal?

Before addressing this question, we will now consider an actual case to illustrate how seriously the Taiwanese indigenous peoples are vulnerable to various harms in current genetic research on them, and in which they finally find a legal basis for their insistence that prior public consent be obtained from their community if they are to be approached for recruitment by any academic research.

## 6 The Case of Kavalan Tribe

A research funded by the National Science Council was launched in 2005 by a group of anthropologists, archaeologists, linguists and geneticists from several prestigious academic institutions to investigate the migratory routes and the likely Austronesian origins of indigenous peoples in Taiwan. Such an academic research is regarded by some to be of great significance as Taiwan is eager to confirm its own distinct identity from China, whose studies tend to suggest that indigenous peoples in the island migrated from the mainland. On the other hand, this kind of research project is regarded by some as highly debatable, or in need of unbiased scrutiny, since those who claim themselves to be a distinct indigenous people have been frustrated by alleged scientific findings that some indigenous peoples in Taiwan are either at the verge of extinction or no longer in possession of enough genetic distinctness to be recognized as a *separate* indigenous people.

The interdisciplinary research in question went under way rather inconspicuously. During recruitment, the ethnic origin of parents was asked for along with the name, gender and genetic sample of every participant. Unlike what the Taiwan Biobank proposes to do, however, there was no acquisition of medical or other phenotypic or lifestyle data, and no follow-up investigation will be undertaken. Nor does the study intend to link the information derived from the data collected with other, more fertile databases, such as the participants' health records kept by the Bureau of National Health Insurance. There is apparently no intention whatsoever on the part of the researchers to mine any further information about the participants and their tribes. The alleged purpose of the study is straightforward, and the limited data-collection plan seems hardly to enable the researchers to engage in any investigation other than the one avowed. All these factors may help explain why the research did not initially encounter as much distrust, or even draw as much public attention, as did the proposal for the Taiwan Biobank Project.

Despite the seemingly modest nature of the research, however, indigenous peoples targeted by the research did not agree wholeheartedly to its apparent innocence. When an investigator contacted a tribe elder of *Kavalan* (also known as *Kavarawan* or *Cavalan*), an indigenous people with a total population of three thousand or so, and asked him for assistance in recruiting sample donors from his scattered tribespeople in early 2007, the elder expressed concern about collection of blood samples.

Aware of the growing uneasiness about blood sampling among indigenous peoples, the project's principal investigator settled on the more costly option of collecting saliva, in the hope that collecting something of a supposedly less sacred nature would leave the already hostile nerves undisturbed. Twenty-nine samples of saliva were at last collected in a small Kavalanian village.

The dispute came up when the Kavalanian Development Association, a non-governmental organization devoted to promoting community development of the Kavalan tribe and their fundamental rights, later objected that the research project should have been reviewed and approved by the tribe as a whole. Without such a public or community consent process, argued the Association, the project violated Article 21 of the "Basic Law of Indigenous Peoples" promulgated just recently in 2005, which provides that "[t]he government or any private party shall consult indigenous peoples and obtain their consent or participation when undertaking land development, resource utilization, ecological conservation, or academic research in the lands of indigenous peoples, and shall share with indigenous people benefits generated therefrom." In addition to this procedural issue, the Association also argued, among other things, that the Kavalan people do not need outsiders to narrate their tribal history. From their past experiences, they came to believe that genetic research projects aiming to tell the origins of indigenous peoples tend to do more harm than good to the peoples they study.

Leaving aside these objections, the research also suffered from flaws during recruitment in failing to abide by familiar ethical principles endorsed by international organizations for research involving human subjects. It turns out that the individual consent given by the twenty-nine sample donors was obtained through a poorly conducted process: the informed consent form is brief and meager in content (just one short sentence in each of the entries for research purpose, method, and possible risks and benefits), and far from meeting the ethical standards for research practice (such as requirement of informed consent, protection from undue risks, guarantee of the right to withdrawal, and equity in the selection of participants) that have been followed by academic communities worldwide in keeping with basic democratic values (such as personal autonomy, beneficence/non-maleficence, and justice). Moreover, according to news report, an elderly woman pointed out that she was not even asked to read the consent form before she signed it and allowed her saliva to be taken. Still worse, the sample donors did not even receive a copy of the signed consent form (where their pertinent rights as subjects are to be stated and explained). These flaws, together with the aforementioned provision by Article 21 of the Basic Law, gave the Kavalanian Development Association good reasons to file, with signed endorsement by the sample donors, a formal request that they be withdrawn from the study and that their biological samples be returned or destroyed.

In April 2007 the Kavalanian participants of the research had their saliva samples returned, which were then flushed away in a ditch publicly in a ceremony held in their village. Like the controversy over the Taiwan Biobank Project, this event also found its way to become a headline with a full-page coverage in a national newspaper.<sup>13</sup> And it was hailed in the news as a "leap forward" for human-rights protection in Taiwan.

## 7 A “Leap Forward”?

Whether this is a genuine “leap forward” for human-rights protection in Taiwan depends, in our view, on whether concrete measures for reform will be taken to ensure that when indigenous people are approached for individual informed consent to participate in research projects, they will be treated, to say the least, with no less respect than has been enjoyed by members of better-off populations.

There are two importantly different arguments for such “egalitarian” measures. One argument is equality-based in an abstract way: appealing to the ideal of *equal citizenship*, to the equal status of everyone *qua* citizen in abstraction from the social group(s) he or she belongs to, it insists that all citizens should be treated as “free and equal” in a Rawlsian sense. But such an argument can by itself shed little light on how precisely to protect legitimate interests of indigenous peoples, in particular, and their members in the age of genetic research. The other argument is also equality-based, but with weighted consideration of *de facto* inequalities that have drastically disadvantaged minority groups: it draws special attention to long-entrenched political, economic and educational *inequalities suffered by indigenous peoples*, and calls for special arrangements to enable their members to make effective use of the right to equal respect and concern.<sup>14</sup> The legal requirement in Taiwan that prior community consent to academic research on indigenous peoples be obtained in the first place may be seen as an indispensable part of such special arrangements.

This requirement is ethically justified not only in the context of genetic (or medical) research whose expected potential for the development of new drugs or treatments raises issues about benefit-sharing that have to be discussed and settled through communal deliberation. It is also ethically justified in the context of genetic research of a kind that does not have such potential, as the Kavalan case described above sufficiently demonstrates.

The Kavalan case is reminiscent of the Genographic Project, an international collaboration to study human origins and migratory history. In 2005, the National Geographic Society, together with the IBM and the Waitt Family Foundation, launched this five-year endeavor to amass at least 100,000 indigenous and traditional genetic samples from around the world.<sup>15</sup> The goal is simply to identify genetic markers for genealogical relationships among different populations and to chart human migratory routes thereby. This modest study-design was approved by the Institutional Review Board (IRB) at the University of Pennsylvania, and the Genographic Project managed to recruit some 18,000 donors from around the world in its first 18 months. Nevertheless, the Indigenous Peoples Council on Biocolonialism (IPCB), whose mission is to “assist indigenous peoples in the protection of their genetic resources, indigenous knowledge, cultural and human rights from the negative effects of biotechnology,” has strongly opposed this project.<sup>16</sup> Although it is unclear whether any of the Taiwanese indigenous peoples have been recruited under the Genographic Project, several indigenous organizations in Taiwan have participated in IPCB’s petition against it. It is argued that the actual risks of the study outweigh the benefits it could bring to the sampled populations. Scientific evidence may point to the conclusion that indigenous peoples came from elsewhere; and

this could threaten not only indigenous peoples' long-held beliefs that shape their self-understanding, but also their moral basis for sovereignty and collective legal claims, such as land rights and other benefits (the moral basis being that their ancestors have lived in the territory since time immemorial). As one indigenous leader puts it, "We don't need genetic testing to tell us who we are or where we come from. Our creation stories and language inform us of our genealogy and ancestors." The Genographic Project was accused of underselling the risks to individual participants. Eventually, in response both to pressure from indigenous groups and to the recommendations of the United Nations Permanent Forum on Indigenous Issues, the IRB at the University of Pennsylvania suspended its previous approval of the project in December 2006.

Unless the kind of genetic research involved in the Kavalan case and in the Genographic Project can proceed without relying on samples collected from members of the relevant indigenous communities, it must try to overcome the present gridlock by negotiating with these communities, through deliberative procedure, about the ends and acceptable ways of undertaking the research and publishing its results while paying due respect to their already disadvantaged cultures. Moreover, the outcome of such negotiation cannot fall short of community consent insofar as the research is to comply with basic values in a pluralistic democracy. This may look to be a rather controversial claim, for, as indicated earlier in this chapter, in case no community consent was arrived at, individual members of an indigenous community would be deprived of the opportunity to decide for themselves whether or not to participate in the research in question.

However, as Allen Buchanan has argued, liberalism, which places fundamental importance on individual rights, "can accommodate the legitimate concerns about groups and their role in the good life which communitarians and advocates of group rights for indigenous peoples rightly emphasize."<sup>17</sup> In supporting ascription of a collective right to consent to indigenous peoples in Taiwan, we do not have to assume that cultural identity somehow constitute individual identity. Rather, we only need to assume that cultural membership plays an essential role of providing meaningful choices with which individuals can shape their own identity and pursue their own conception of the good life. Thus, given that participation in a genetic research will give rise to significant risks to the already vulnerable indigenous groups in Taiwan, and given that only if these groups are possessed of a collective right to consent (or dissent) can they find adequate protection, it should not be considered detrimental to democratic values if they are ascribed a veto power over individual consent by their members.

The foregoing justification of the indigenous peoples' right to community consent may nonetheless leave room for worries about the tendency of this right to be wielded *paternalistically* in an objectionable way. Aware of this lingering problem, Buchanan suggests that group rights be "embedded in a framework of appropriate individual rights."<sup>18</sup> Matters may be made simpler, though perhaps not easier, in the Taiwanese context if we assume that the right to community consent is to be wielded by a deliberative body composed mainly of indigenous representatives, rather than through some majoritarian decision procedure. This is a reasonable assumption if

it turns out that the Taiwan Biobank Project can reasonably be taken, especially in view of Article 21 of the Basic Law invoked by the Kavalan tribe, to require a similar deliberative process to be incorporated into its regulatory framework for specific research projects that apply for usage of data gleaned from the indigenous population. If so, then what needs to be done is to ensure that representatives of the deliberative body in question be selected through democratic means, and that they follow a procedure which is sensitive to diverse opinions held by individual members of the indigenous population, and which is properly designed to meet necessary conditions for informed and fair-minded public deliberation. Although it is as yet unclear how this is to be done in the Taiwanese context, it seems plausible to say that this is the kind of approach that is worth trying out if the collective interests of Taiwanese indigenous peoples are to be safeguarded and promoted in the age of genetic research.

## 8 Public Deliberation at the National Level

Focusing on the Taiwan Biobank Project, we find that the justification suggested above for conferring a right to community consent upon the indigenous peoples does not seem to apply in the case of other target populations without a long-lasting history of subordination: the indigenous peoples are the least-advantaged population in Taiwan, and no other target population's interests are similarly put at significant risk. Nevertheless, at least public deliberation at the national level is called for if such a national project is to secure public trust and support. The question is whether O'Neill's thesis we saw earlier about the *priority* of public over individual consent holds in the Taiwanese context, or, in other words, whether public consent, to be acquired through public deliberation at the national level, is morally required before the Taiwan Biobank Project can go ahead with its recruitment process.

O'Neill is primarily concerned about the complexity of “*systems* for collecting, storing, using and disclosing data” that large-scale biobanking projects aim to establish. Indeed, such systems, or internal arrangements as we call them, go well beyond an unsophisticated lay person's ability to comprehend so that he or she is cognitively in a poor position to determine whether such arrangements are adequate for the purpose of privacy protection. This makes it doubtful whether individual *informed* consent is really possible in this case. And there are other often-discussed problems that also make this doubtful. For example, data stored in a biobank will be used for a variety of research purposes which cannot be exhaustively specified in the consent form; consequently, potential participants in the biobank cannot be guaranteed at the time of recruitment that their conception of the good life will be fully respected by future usage of the data they contribute to the biobank. Although different proposals are made to tackle this indeterminacy in data usage, the problem itself may be taken to show that individual consent in the context of large-scale biobanking cannot amount to *informed* consent.

Solution to problems like these seems to lie in the internal arrangements of a large biobank, rather than in the contents of the individual consent form. O'Neill is definitely right about this. And provided that the internal arrangements are beyond ordinary lay people's comprehension, it seems also reasonable to require that they be subjected to the scrutiny and deliberation of a public forum to make sure that the biobank in question will operate in ways that do not betray or exploit the good will or altruistic motivation that is supposed to lead the (less than adequately informed) individuals to participate. However, as we noted earlier in connection with O'Neill's priority thesis about public consent, there may be people who consider the biobanking endeavor so important for the well-being of future generations that they are willing to participate regardless of whether their personal privacy has been adequately protected, or their conception of the good life fully respected. Call these "overwhelmingly altruistic people." It may not be difficult to find these people in the Taiwanese society: a recent finding by the Center for Survey Research at Academia Sinica shows that out of 1,089 interviewed in a nationwide telephone survey conducted in 2005, 76.7 % stated that they would be inclined to donate blood samples to a biobanking project if privacy protection is assured, and 51.3 % were still willing to do so after they were alerted that leakage of personal genetic information might be a serious concern. Now suppose public consent at the national level is required but turns out to be withheld after the Taiwan Biobank Project has been examined by a public forum. Then, *unless* overwhelmingly altruistic people belong to especially vulnerable minority groups such as the indigenous population, there doesn't seem to be any good moral reason compatible with the liberal stance on the importance of individual rights to discredit their complaint that the forum's decision to withhold public consent is objectionably paternalistic.

However, as noted earlier, there are concerns other than the adequacy of means to ensuring the single end of privacy protection, and there is a distinction between external and internal regulatory arrangements. People who challenge the justice of spending substantial amount of public money on the search for some magic cure of illness at the genetic level rather than on more familiar toxic-control programs may legitimately bring their concern to the national level and seek to change *externally* the current allocation of public resources. People who are worried that their samples and data might be used in ways that conflict with their conception of the good life may push for an *external* policy or legislation prohibiting medical research on certain topics.<sup>19</sup> After these issues have been settled *externally*, public deliberation on relevant *internal* arrangements need only to yield reasoned judgments, pros and cons, that may enable individuals to decide for themselves as to whether the Taiwan Biobank Project is worthy of their trust and participation. However, the institutional capacities of public deliberation on arrangements *internal* to a biobanking project are limited in scope: they can only be exercised when the kind of *external* arrangements described above have already been put in place. That is to say, as far as (what we hold to be non-binding) deliberative outcome at the national level is concerned, a minimum set of settled external arrangements are a necessary background against which public deliberation on the *internal* arrangements of a biobanking project can meaningfully proceed.

## 9 Conclusion: A “Two-Tiered, Double-Standard” Scheme

What we are suggesting in outline above may be called a “two-tiered, double-standard” scheme for public deliberation in the context of the Taiwan Biobank Project. Public deliberation at the *national* level is indeed necessary if the project is to attain public trust and support, but we think it should *not* be put in a position to yield an outcome taken so strongly as to amount to public consent or dissent. For taking the deliberative outcome at the national level so strongly may usher in dangers of paternalism *incompatible* with respect for individual rights, contrary to the increasing importance placed by the Taiwanese society on such rights.

However, whereas it has been duly recognized in Taiwan that individual rights should be equally respected for all citizens, the *equal value* of these rights for all citizens has yet to be ensured in practice. The Taiwanese government has tried to adopt policies of various sorts to rectify the long-entrenched inequalities befalling the indigenous population, but effects of these inequalities are inevitably still causing the population familiar undeserved disadvantages besieging other indigenous peoples elsewhere in the world. Under such circumstances, members of the population may very likely be unable to wield their (legally recognized) individual rights as effectively as members of other, better-off populations in Taiwan. Thus, in the context of the Taiwan Biobank Project, it is far from enough merely to guarantee “equality of opportunity” for every citizen to participate in the public deliberative process at the national level or at least have an indirect influence over its outcome.

As the Kavalan case has brought to the attention of human-rights advocates and concerned scholars in Taiwan these days, it is arguable that the indigenous population is in fact legally entitled, according to the Basic Laws promulgated in 2005, to demand that collective consent be obtained from local indigenous communities before the Taiwan Biobank Project begins recruitment in them. In this chapter, we have tried to make a moral case for this claim to community consent, namely, that demand for such consent, to be obtained through public deliberation at the *local* level, is in any case *morally* justifiable if the indigenous population is to safeguard its legitimate interests against significant risks it will be particularly exposed to by the kind of genetic and medical research that will utilize the Taiwan Biobank. As far as we can see, no other population targeted by the project deserves a similarly strong moral claim to such community consent.

Accordingly, a kind of public deliberation at the local level on the Taiwan Biobank Project needs to be arranged specifically for the purpose of protecting the indigenous population. How this is to be arranged, and whether it should engage only the local, tribal communities where recruitment will be conducted, or the indigenous population at large, are matters to be worked out by the relevant indigenous stakeholders, who must face up to the unprecedented challenge of deciding how the collective right conferred by the Basic Law is to be wielded in democratic ways. Nevertheless, it seems reasonable to say here that, in the order of time, this local deliberative process for reaching community consent or dissent should be arranged to start off prior to public deliberation at the national level on the Taiwan Biobank Project. For not only will this provide members of the indigenous population with an

opportunity, welcomed by indigenous non-governmental organizations, to generate (and then accumulate) their own distinctive resources for public discourse and rationation on the ethical aspects of research involving them as subjects, but it will also help heighten the general public's sensitivity to issues of distributive and restorative justice that should be taken into account by the pursuit of common good in a society like Taiwan determined to oppose exploitation and manipulation of minority groups. Hopefully, with additional positive actions taken by the government to assist them in building up capacities for initiating their own issues and concerns and communicating with citizens from other social groups in public deliberation, members of the Taiwanese indigenous population will then be empowered to participate in deliberative forums at the national level more effectively as free and equal citizens.

## Notes

<sup>1</sup> Science and Technology Advisory Group of Executive Yuan, *Policy Statement on Constructing an Island of Biomedical Technology*, April 6, 2005, [http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=&grpId=5&vroot=&cntgrp\\_ordinal=00060004&cnt\\_id=400](http://www.stag.gov.tw/content/application/stag/general/guest-cnt-browse.php?ico=&grpId=5&vroot=&cntgrp_ordinal=00060004&cnt_id=400).

<sup>2</sup> *China Times*, Jan. 7, 2006, at A5.

<sup>3</sup> More information on the topic can be obtained from the website of the Popular Alliance Against the National IC Card System, [http://www.tahr.org.tw/noidcard/analysis\\_paper/fact\\_sheet.html](http://www.tahr.org.tw/noidcard/analysis_paper/fact_sheet.html).

<sup>4</sup> J. Y. Interpretation No. 603 (2005).

<sup>5</sup> S. J. Chen, "Indigenous Peoples in the Test Tube," *Medical Look* 23 (1998), pp. 45–47.

<sup>6</sup> Allegations along this line were made in a (videotaped) panel discussion by an indigenous health professional.

<sup>7</sup> Registration form on file with the authors.

<sup>8</sup> *China Times*, Jan. 23, 2006, at A10, and Jan. 24, 2006, at A8.

<sup>9</sup> See Onora O'Neill, "Informed Consent and Genetic Information," *Studies in History and Philosophy of Biological and Biomedical Sciences* 32 (2001), pp. 689–704; and *Autonomy and Trust in Bioethics*, Cambridge University Press, 2002.

<sup>10</sup> See Donna Dickenson, "Consent, Commodification and Benefit-Sharing in Genetic Research," *Developing World Bioethics* 4 (2004), pp. 109–124.

<sup>11</sup> O'Neill, "Informed Consent and Genetic Information," p. 701, original emphases.

<sup>12</sup> *Ibid.*, p. 689, emphasis added.

<sup>13</sup> *United Daily*, April 2, 2007, at A1 and A3.

<sup>14</sup> For the second kind of equality-based argument, see James Bohman, *Public Deliberation: Pluralism, Complexity, and Democracy*, The MIT Press, 1996, esp. Chapter 3.

<sup>15</sup> For more detailed information on the Genographic Project, see <https://www3.nationalgeographic.com/genographic/index.html>.

<sup>16</sup> For more information on IPCB's position on genetic research, see [http://www.ipcb.org/issues/human\\_genetics/index.html](http://www.ipcb.org/issues/human_genetics/index.html).

<sup>17</sup> Allen Buchanan, "Liberalism and Group Rights," in Jules L. Coleman and Allen Buchanan, eds., *In Harm's Way: Essays in Honor of Joel Feinberg*, Cambridge University Press, 1994, pp. 1–15; quotation from p. 11. For similar defenses of liberalism as compatible with attribution of group rights, see, e.g., William Kymlicka, *Liberalism, Community, and Culture*, Oxford University Press, 1989, and more recently, Steven Wall, "Collective Rights and Individual Autonomy," *Ethics* 117 (2007), pp. 234–264.

<sup>18</sup> *Ibid.*, p. 13.

<sup>19</sup> Of course, people who weigh informational privacy more heavily than research may well think it imperative to promote an *external* legislation that prohibits any unauthorized data linkage among different databases.

# Genetic Resources, Genetic Democracy and Genetic Equity

Keekok Lee

## 1 Introduction

This contribution will examine the link between genetic resources and genetic democracy and equity in the light of the Human Genome Project (HGP). It will explore certain notions and distinctions crucial to the elucidation of such a link, namely, those of *homo faber*, biotic artefact, the humanisation of nature as opposed to the naturalisation of humanity, the processes of reproduction as opposed to the procedures of production in order to demonstrate the transformation of the discovery of human DNA to become genetic resources. It will in turn show how such a transformation can be incorporated into the framework of democracy (as it is understood by the major democratic countries in the world today, such as the EU, the USA and India). However, it will also argue that while the incorporation may satisfy the formal requirements of the liberal-democratic/capitalist-economic order, it may not be able to satisfy the value of equality and equity and, furthermore, that it may transform a class-based meritocratic society into a caste-based hierarchical one.<sup>1</sup>

## 2 Homo Faber

Humans throughout its evolution have used tools to transform the world.<sup>2</sup> At one extreme, our hunter-gatherer ancestors used primitive tools primarily to ensure their survival, while at the other, our more modern forefathers used increasingly more and more sophisticated tools not merely to ensure survival but to enable people to satisfy their more and more complicated desires for enriched living as well as to undertake their chosen projects of self-realisation, be these in science, art, industry, commerce, leisure or consumption in general. *Homo faber*<sup>3</sup> may thus be said to be a fundamental category of human agency in modernity, as evidenced by the increasingly powerful technologies generated by discoveries in the basic sciences during

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K. Lee  
University of Manchester, England  
e-mail: keekok.lee@manchester.ac.uk

the last hundred and fifty years, such as physics, chemistry and of late biology, to help human-kind to control and manipulate the natural world in order to fulfil its projects of improving material well-being in particular or of self-realisation in general. The life of fabrication, far from being a subordinate, subsidiary, though necessary human activity, has become a central pre-occupation, so central that fabrication becomes the very essence and constitution of human nature in the age of modernity and progress.

In a world heavily transformed by human fabrication, human existence itself cannot escape being transformed by its own fabrication in all its diverse activities. In other words, this is to say that the *homo* which plays or day-dreams acts in a world that has been transformed by human-kind's continuous process of creative fabrication through its labour and its tools/technology. The case is sometimes put thus: the cultural history of human-kind is indeed the history of its technology and the different artefacts which different forms of technology bring forth. Bergson has articulated it well:

In thousands of years, when, seen from the distance, only the broad lines of the present age will still be visible, our wars and our revolutions will count for little, even supposing they are remembered at all; but the steam-engine, and the procession of inventions of every kind that accompanied it, will perhaps be spoken of as we speak of the bronze or of the chipped stone of prehistoric times: it will serve to define an age. (1911, p. 146)

The thesis that the identity and essence of humanity is constituted by the activity of fabrication amounts to this: it is not the claim that humans only manufacture artefacts and never play, make love, eat, write novels outside of the activity of fabricating things. Rather, it is to say that even when people play, eat, make love, or write novels, they are doing these things in the context of a fabricated, artefactual world. On the back of *homo faber* rides *homo ludens*. Take writing. In the past, it was done with reed and papyrus, equipment with a low level of artefacticity. Today many (including this author) use the computer as a word processing machine, which is *par excellence* a highly technologised artefact. Fabrication penetrates every activity people engage in, including the act of breathing, as the air they breathe may increasingly be air-conditioned and purified. As technology develops more radically and powerfully, *homo faber* structures and creates a more and more artefactual world within which all human activities necessarily take place. Even the activity of walking in the mountains or in the wilderness is not exempt, although walkers may convince themselves that it is. It is true that they are using their feet, their own power of locomotion. But the boots on their feet, the socks which encase the feet, the waterproof they wear, the sleeping bag they crawl into at night, the rucksack on their back are probably made of synthetic substances of one kind or other. As walkers, workers, lovers or whatever, we are what we are capable of doing through our labour, our science and our technology.

The procedure of fabrication and its products transform non-human nature, and in so doing, also transform ourselves. Whereas other civilisations at other times in human history have chosen other routes to self-realisation, be it political or theological and, as a result, have subordinated the activity of fabrication to these other ends, modern civilisation has committed human-kind to self-realisation *via* fabrication

itself. The price paid for being *homo faber* is, increasingly, in the terminology of Marx and others, the near-total, if not the total humanisation of nature and the naturalisation of humanity itself. However, I will not say any more about this distinction here but leave it to a later section.

### 3 Biotechnology and Biotic Artefact

In this context, one is talking only about human artefacts.<sup>4</sup> An artefact may be briefly defined as the material embodiment of human intentionality.<sup>5</sup> Another way of making the same point is to elucidate the notion in terms of Aristotle's four causes. Take a statue as the paradigm of an artefact – its material cause is marble, its efficient cause is the sculptor, its formal cause is the blueprint either in the sculptor's head or sketched out on a piece of paper, and its final cause is the purpose for which the statue has been commissioned, such as to commemorate an event or a national/municipal celebrity.

The last three causes refer to human agency and its intentionality; the first to the material medium in which the intentionality becomes embedded. Without human agency and its intentionality, there would only be matter. With the extinction of the human species and its unique type of consciousness, the artefacts which humans have created out of matter would also disappear, leaving only matter behind. The Taj Mahal, as a mausoleum, (which Shah Jahan built in commemoration of his favourite wife, an exquisitely conceived and constructed building made of marble which the world, since its appearance, has come to admire as a great work of art) would no longer exist; only the marble (as a naturally occurring substance), from which it has been made, would continue to exist, until the natural actions of wind, rain, plants and animals finally wear down the marble to soil. The Taj Mahal is an artefact; as such it is a human construct and construction and, therefore, necessarily it has neither meaning nor existence in the total absence of human consciousness.<sup>6</sup>

Artefacts are normally considered to be abiotic or exbiotic, such as a marble sculpture or a wooden chair. However, artefacts may also be biotic. Human-kind, in its long history of domesticating certain animals and plants, has transformed the ancestors of these organisms from being naturally occurring beings to become biotic artefacts. To see how it is conceptually possible to do so, let us further elucidate the notion of artefact, this time, not so much in terms of Aristotle's four causes, but in terms of distinguishing between two theses of teleology, namely, intrinsic/immanent teleology and extrinsic/imposed teleology. The former is related to the fact that naturally occurring organisms are autopoietic beings, which exist 'by themselves' as well as 'for themselves'. This is to say that plants and animals in the wild have come into existence, continue to exist and go out of existence (in principle) independently of human intervention; they also strive to keep alive, to reproduce, etc., not to fulfil any end or purpose of any external agents (including human agents), but entirely and only to maintain their own functioning integrity. Organisms, in living 'for themselves' (by sustaining and reproducing themselves), are realizing

their respective *tele* as individuals and as members of their species.<sup>7</sup> In so doing, they exemplify the notion of intrinsic/immanent teleology.

Attempts by humans to turn naturally occurring organisms into biotic artefacts exemplify the thesis of *extrinsic/imposed teleology*. For millennia they relied on what may be called the craft-technology of selective breeding. However, in the first half of the twentieth century, these traditional methods were radically overhauled by a new technology, which was informed by the theoretical understanding given by the basic science of classical Mendelian genetics and the gene-chromosome theory. The last quarter of that century also witnessed the arrival of a yet more powerful technology, called biotechnology or genetic engineering, which is informed by the theoretical understanding given by the even more basic sciences of molecular genetics and molecular biology.<sup>8</sup> It is more powerful precisely because it allows human-kind to cross boundaries between species and kingdoms by manipulating organisms, no longer at the level of whole organisms but at the molecular – DNA – level. For instance, one can insert into bacteria, DNA that may belong to the human genome. One can get cows to produce human proteins in their milk. These examples illustrate the procedure of transforming naturally occurring organisms, as in the case of the bacteria, to become biotic artefacts, or in the case of the cow, which as a domesticated animal is already a biotic artefact, to embody a deeper level of artefacticity.<sup>9</sup> The transgenic cow, unlike the more usual domesticated cow, has been commandeered by humans to use its autopoietic powers of self-maintenance to produce, not cow's milk, but milk which contains a human protein. In other words, biotechnology has succeeded in severing, in the clearest manner possible, what has been an inseparable link between being an organism, which exists 'by itself' (as naturally occurring evolved being whose existence is entirely independent of human intention and intervention), and one which exists 'for itself' (as an autopoietic being which strives to maintain its own functioning integrity and to reproduce itself). Up to even twenty-five years ago, the distinction between 'by itself' and 'for itself' was one that could only be made intellectually but not empirically. But recently, biotechnology has managed to sunder them as a matter of fact.

#### **4 The Humanisation of Nature and the Naturalisation of Humanity**

Today's sophisticated technologies, such as information technology, nanotechnology as well as biotechnology enable us to control and manipulate, more radically than ever before, nature both abiotic and biotic. Biotechnology helps us to turn (non-human) living organisms which historically are naturally occurring evolved beings into biotic artefacts as we have seen, that is to say, to humanise biotic nature making it over to embody our human ends and intentions. As a result, natural evolution of non-human organisms may now be by-passed. However, biotechnology goes beyond that with the recent first completion of the human genome project; this project enables us now to regard ourselves as no more than one living organism

amongst others and to transform ourselves into biotic artefacts, in the same way as we have transformed certain bacteria or mice into biotic artefacts. This amounts to the naturalisation of humanity. It is now technologically possible for us to remove certain DNA sequences deemed harmful from a particular human genome, or to insert into it others deemed desirable from another. Ethical considerations are invoked as constraints to stop this possibility in its track, but increasingly these are being eroded or loosened in order to enable us to use this new set of potent technologies to advance physical well-being as well as to realise ourselves in ways we see fit as living organisms.

Just to give one example of how these new currents have appeared which are breaking down the ethical barriers previously erected: the least controversial of the uses of biotechnology is as diagnostic and therapeutic tools in medicine. The over-arching goal of modern science and technology is, after all, to promote human material/physical well-being of which good health is clearly a part. Furthermore, the axiomatic goal in medicine itself is to save and prolong life, to remove pain and suffering when the technological means are available. Society in general, and medicine in particular, consider it unproblematic to use biotechnology to achieve such a highly desirable and desired goal. Tay-Sachs disease, to take an example, is a disorder of fat metabolism involving the degeneration of the nerve cells which leads to blindness, paralysis and death within the first year of life. This highly distressing disease is a single-gene disorder. Genetic counselling is used to prevent the occurrence of the disorder. Beyond identifying the carriers, increasingly, genetic counselling also implies detecting the homozygous state of the embryo (one which has inherited two alleles of the defective gene, one from each parent) in utero. The parents would then be given the choice of abortion. Such a programme has been effective in North America.<sup>10</sup>

## **5 Reproduction, Production and Biotic Artefact**

Until the appearance of biotechnology, human-kind has relied, in the main (and still does), on cultural means to regulate and determine human reproduction. Once the cultural selection is in place, the only technique relied on is copulation, helped in some instances by subsidiary techniques, which vary from culture to culture, like eating the right foods, or saying the right prayers in the hope that there would be success in conception, and that the offspring turn out to have certain desired characteristics. Traditionally, fertility is regarded as a gift of some deity or nature.

Between humans, the technique of copulation may be used intentionally to bring about reproduction or more often, it may not.<sup>11</sup> But as is well known, the intention behind the act of copulation alone is not sufficient in ensuring that reproduction would take place. It is precisely in cases of persistent failure that the recently established biotechnological innovations have been put to use to rectify some of these failures. In so doing, these innovations appear to have transformed the processes of reproduction to become procedures of production.<sup>12</sup>

Take cake-making as the paradigm of production, issuing in an artefact. The confectioner (the efficient cause) chooses the quantity and type of ingredients, the kind of oven and temperature (the material cause), guided by the kind of cake that s/he desires to make (the formal cause) for the purpose of celebrating a birthday or a wedding (the final cause). In contrast, human reproduction, under non-technological conditions, do not approximate or satisfy at least two of these conditions. The man and woman attempting to reproduce may at best be characterised as the efficient cause; they may even be said to have a final cause in mind, in the sense that they would like to cement their relationship by having a child.<sup>13</sup> But as they have no control over the sex or the genetic inheritance – the material cause – of any offspring they may eventually have, they cannot be said to be the formal cause either. The formal cause and the material cause appear to lie within the union of a particular sperm and a particular egg to form the embryo, which then develops into the infant to be born nine months later.

But under biotechnological conditions, reproduction is superseded by production. The efficient cause includes the woman or man who desires a child, the donor of the sperm or egg, the team of doctors and technicians, and in some cases, another woman willing to act as surrogate birth mother.<sup>14</sup> The person who desires to have a child is able, in principle, to choose its sex and some, if not all, of its genetic inheritance – the material cause. The choice in turn is guided by the kind of offspring deemed to be desirable – the formal cause. The final cause is the desire for a child, using whatever technological means are available, which society may have or indeed, sometimes, not have sanctioned.

## 6 Genetic Democracy and Genetic Resources

Given the technological possibility, arising from the HGP, of turning human beings into biotic artefacts, society in general is anxious to distance itself from the socially and politically unacceptable implications of eugenics in the last century like Nazi eugenics (in Germany), racist eugenics (in the USA) and classist eugenics (in England and even in some Scandinavian countries). Scientists today could claim that these earlier eugenic programmes were based on too simplistic an understanding of the genetic basis of human behaviour anyway. This means that the science of genetics itself, as we know it today, is neither implicated nor discredited by the previous poor science.<sup>15</sup>

The old eugenics aspired to transform society genetically, relying on crude social engineering ultimately to deliver the utopian results. In its most extreme form, the Nazis had to kill off (or in today's language, 'to engage in ethnic cleansing') those considered unfit to contribute to the gene pool of their good society. The new eugenics made possible by biotechnology induced by molecular biology is presented differently; it is said to enlarge individual choice and to extend the range of possible human intervention, sometimes referred to as *laissez faire* eugenics. The narrower medical remit renders the new eugenics morally palatable by presenting such a use

of genetics as a 'guarantee to all human beings an individual and natural right, the right to health.'<sup>16</sup> The Office of Technology Assessment (USA) in its 1988 report on the HGP endorsed the argument that 'individuals have a paramount right to be born with a normal, adequate hereditary endowment' (US National Research Council, 1988, p. 86).<sup>17</sup> In this way, the biotechnological implications of the HGP are rendered compatible with the liberal democratic framework within which citizens enjoy the unimpeded human right to avoid pain or disease.

However, the possibilities go beyond this to other characteristics regarding gender, beauty, intelligence which if left genetically unaltered may lead, it is claimed, to less contentment or happiness. These possibilities challenge and transform the old nature/nurture controversy itself.<sup>18</sup> We know that physical stature is affected by nurture via nutrition as shown by the statistics regarding the height of Japanese children pre and post World War II; however, biotechnology offers an alternative more direct route, the genetic one, by modifying the gene for height when that gene is identified.<sup>19</sup> Nature in the nature/nurture controversy has been understood until of late to refer to a variable regarded as altogether beyond human control and manipulation, and therefore, to imply fate or destiny, while nurture is taken to imply freedom of action, as one can take certain steps to modify the environment in which the young grow and develop. However, biotechnology has challenged this; it gives rise to the view that humans could also control nature directly or just as readily, if not more readily and simply than nurture. It promises eventually to deliver us 'designer' babies in terms both of physical and mental characteristics.<sup>20</sup> However, at least for the time being, going down this route overtly is ethically frowned upon, in countries in the West, unless the genetic intervention is medically framed, as we saw earlier. It is morally acceptable to ensure that people do not suffer from distressing conditions caused by defective genes and, perhaps, to eradicate such genes eventually from the human gene pool, but it is not morally acceptable to manipulate genetic material to ensure that only 'perfect' babies are born embodying whatever society (or a section of it) deems to be desirable traits. But the situation could well soon change.

Genome projects, whether of the human or other organisms, have directly raised the matter of turning what are discoveries in the basic molecular biological sciences into genetic resources *via* the thorny issue of their patentability. Scientists have identified human DNA sequences in the HGP, although many of these are not complete gene sequences with known protein function but partial gene sequences with no known function, referred to as ESTs (expressed sequence tags).<sup>21</sup> The Patent Office in the USA as well as the patent offices of the respective EU countries have been inundated with applications from biotech bodies and companies to patent not only transgenic organisms, but also complete DNA sequences with known functions, as well as, indeed, of ESTs. Patentability in this domain rests on two legs: the general economic one that patenting bestowing unique ownership on the patentee for a limited period of time benefits society economically in the long run, while the philosophical one is based on the recognition that ontologically the item to be patented is not a naturally occurring phenomenon, which basic science has discovered, but a human artefact. The on-going attempt to patent even ESTs is, therefore, a crucial step in the ontological transformation of DNA sequences which may be said to

be naturally occurring to become (biotic) artefacts. Artefacts, such as machines, buildings, artificial diamonds, plutonium, are paradigmatically economic resources. If DNA sequences are patentable, then they are clearly an economic resource. As such they are commodities, and people with the desire for them and with the money to spare, can, in principle, purchase them for their own ends, whatever these may be, including the end of genetic enhancement, not merely for themselves but also for their offspring.

## **7 Genetic Resources and the Value of Equality/Equity**

A state which is liberal democratic in its politics, and welfare capitalist in its economics (such as countries in the EU) ensures that its citizens are guaranteed access to human DNA sequences, as genetic resources, as a matter of human right, if these are used for the purpose of pain relief and disease elimination. But such states have not yet pronounced on extending the same perspective to the enhancement of characteristics which are not so directly involved with either pain or disease. Ethical constraints apart, such an extension may never come about, as it would be considered to be too expensive. If so, such states as well as others, which are not welfare capitalist in orientation but are wedded to unrestrained market capitalism, would simply leave such matters to individual choices. In other words, those who want such enhancement and can afford them should be allowed to do so.

This would be in keeping with the concept of equality of opportunity as generally understood. The state guarantees the formal freedom for enhancement – there should be no legal prohibition, but the state does/should not guarantee that the desire for such enhancement be met through public funding in order to ensure that every citizen achieves the desired outcome. Nor would it be politically/morally acceptable to prevent those with the material means to procure such enhancement from doing so, as prohibition would amount to an unjustified restraint on freedom of individual choice. The logic of such ideological thinking would eventually, but assuredly, lead to an unequal society where the rich, then, would be ‘gene rich’ and the poor ‘gene poor’. Is this acceptable from the standpoint of equality or equity?

Under normal conditions of human reproduction, the resulting genome of every embryo is like the outcome of a lottery – when the particular sperm meets the particular egg and fertilises it, thereby setting in motion the complicated genetic exchange between the two of them, no science could predict and no technology could control the genetic inheritance of the zygote, whether the reproduction occurs between couples who are rich or couples who are poor. This uncertainty is borne out by the apocryphal story about the Hollywood celebrity who would like Einstein to father her child, being under the mistaken assumption that the child would necessarily inherit her looks and Einstein’s brain. Einstein was reported as having wittily pointed out the possibility that the poor offspring could well inherit his looks but her brains. In that sense, each of us stands an equal chance, in theory, of being brainy/stupid, ugly/beautiful – Einstein did not after all come from a family known

to have exceptional brains like his own, nor is it the case that all Nobel physics winners invariably produce Nobel physics winning offspring.

Endowments which belong to nature, which are beyond human control and manipulation are the given of life; some call these fate or destiny, others luck, either good or not so good. However, what belongs to nurture is held to be within human control and manipulation to a greater or smaller extent, as already observed. Politically in a democracy not wedded to naked market capitalism, it is considered legitimate to agitate the state to ensure that all its citizens have equal material access to those resources which would enable everyone to grow and develop into healthy, educated beings.

In other words, it makes both conceptual and moral sense to go beyond equality of opportunity understood as merely embodying the formal right to do something, also to agitate for rights in the material sense in contexts where human control and manipulation are possible; it follows that it makes no sense to do so in contexts where control and manipulation are beyond us. However, with the advent of biotechnology, genetic inheritance, which was once beyond control and manipulation, has been transformed into genetic resources readily available to those with appropriate economic resources.

Equality of opportunity is a concept which is tied up with that of meritocracy. On the surface, it satisfies one's sense of fairness. Take higher education: according to it, no one should be denied a university education because of inadequate parental income as the only causally and morally relevant criterion for exclusion is inadequate academic intelligence and unsuitability for such an education. Hence society feels it is right to help bright students from financially poor family background through scholarships or bursaries. In the present meritocratic order, upon graduation, students are more likely to get more prestigious, better paid jobs, and as a result, to acquire/marry partners who are similarly advantaged. In the new meritocratic order of the future, such citizens could then choose to enhance the genetic inheritance of their offspring, as they can afford to buy into the market of genetic resources. Their offspring would then not only enjoy a privileged upbringing but also privileged enhanced genetic inheritance—they would then be the equivalent of Plato's philosopher kings and queens.

Imagine yourself as the admissions tutor to a prestigious university in the new economic-genetic order. Today, many sensitive admissions tutors, for instance in the UK and France, are already aware that by using the so-called objectively fair and causally relevant criterion of examination grades (plus interview), they run the risk of admitting a disproportionate number of students from privileged backgrounds, who have been sent by their parents to the right schools for both intellectual as well as social grooming. The concept of positive discrimination is then often invoked in order to re-address this problem of exclusion. May be an analogous situation would arise in the economically-driven genetic future. Unless conscious effort is made to prevent systematic and systemic exclusion of the genetically unenhanced, the futuristic order would be a severely hierarchical one, with little or no social mobility. The new Platonic philosopher kings and queens would form the new dynasty/aristocracy or the new Brahmin caste; the rest would become the new lower

casts or even outcast. Meritocracy would transform itself from a class-based notion to a caste-based one.

In other words, paradoxically, the logic of meritocracy leads to that of aristocracy. Historically, in Europe, at least, the former opposed the medieval feudal order, within which birth uniquely determined one's place in society; progress consisted of overthrowing that old order, instituting the new based no longer on the accident of birth, but on merit. A class-based society is considered to be morally superior to one based on caste. However, as history has also shown, a class society, though in principle, permitting perfect social mobility, in practice, has led to an unequal one within a framework primarily liberal in politics and economics. Such inequalities would be augmented and become even more deeply entrenched when the human right to genetic enhancement, open to those who can buy into the genetic resources market, is added to the already recognised list of freedoms of individual choice. Such a society which is liberal both in the political and economic domains must now confront the implications of the biotechnological possibility of genetic enhancement, which goes beyond the relief of pain and the elimination of disease, especially the implication for equality leading away from the logic of class inherent in meritocracy to its paradoxical opposite, the logic of caste.

## 8 Conclusion

Genetic resources in the context of genetic enhancement which goes beyond the elimination of pain and/or disease may be readily accommodated within a liberal political and economic order in terms of the notion of freedom of individual choice. However, such an approach could lead to a consequence worrying to those who are concerned with the value of equality or equity, as it can, paradoxically, lead such a society from being essentially a class-based meritocracy to being a caste-based one. Modernity prides itself on the notion of progress, which in the historical political context, has meant substituting individual merit and effort for feudalism based on birth. In this so-called post-modern age, it looks as if biotechnology within a liberal political/economic order could lead us to come full circle to a new feudal order.

## Notes

<sup>1</sup> However, this analysis should not be taken to imply that the author endorses either genetic or technological determinism – its very limited remit is merely to explore the logic of liberal genetics in the light of the Human Genome Project, drawing out explicitly the conclusions which such a logic entails.

<sup>2</sup> This is an acknowledgement of the fact that humankind throughout its history has made artefacts, and also implies that artefacts embody different degrees of artefacticity, depending on the kind of technology available at any one period of history. (On the subject of degrees of artefacticity, for details, see Lee, 2005.)

<sup>3</sup> For details, see Lee [1996].

<sup>4</sup> This is because animals also make artefacts, such as the beaver, its dam or the ants, their nest. However, the conceptual analysis which follows for the concept of human artefact cannot unproblematically be applied to animal artefacts, as animals lack the kind of consciousness peculiar and unique to humans.

<sup>5</sup> For a more detailed philosophical analysis of the concept, see Lee (2005), Chapter 1.

<sup>6</sup> For details of this point, see Lee (2000).

<sup>7</sup> In this context, *telos* or *tele* (in the plural) is used to refer to the developmental programme, which inheres in every individual organism as a naturally occurring being. For example, an acorn, in accordance with its *telos* would become an oak sapling, which would grow eventually to be a mature oak tree, producing in turn its own acorns.

<sup>8</sup> For detailed philosophical treatment of these two revolutions in genetics in the twentieth century and their respective technologies, see Lee (2005).

<sup>9</sup> For degrees of artefacticity, see Lee (1999).

<sup>10</sup> This case is not tangled with other socially thorny problems, which could smack of either racism or 'ethnic cleansing.' For example, in the USA, people who are carriers of the sickle-cell trait and sufferers of sickle-cell anaemia are predominantly Americans of African descents. In the 1970s, the US Department of Defence had a policy of excluding such carriers from the Air Force Academy even if they did not manifest the disease. This would appear to amount to racial discrimination. Neither does Tay-Sachs disease present any biological complexities like those associated with other single-gene disorders such as the thalassaemias. Beta-thalassaemia which affects the peoples of the Mediterranean also provides some protection against malaria – in other words, the gene has deleterious as well as good effects.

The National Institutes of Health in the USA has of late recommended another single-cell disorder for genetic counselling. One in 30 white Americans is said to carry the recessive allele for cystic fibrosis. This means 1 in 900 chance of an average couple carrying the defective gene, and 1 in 4 chance that its offspring will have cystic fibrosis. See Kleiner, 26 April 1997, p. 12.

<sup>11</sup> To prevent conception, technological means like contraceptive pills or the intra uterine device are, of course, available. Sterilisation, however, does not count as a technological device, but a technique. Sterilisation is analogous to breaking someone's leg except that the former today is done with a high-tech tool under high-tech conditions in a medical context, whereas the latter (in the eyes of the law) is frowned upon whether accomplished with a kick or a rod of steel.

<sup>12</sup> The term 'processes' is used to refer to what take place naturally in the absence of human intervention and manipulation, while the term 'procedures' is used to refer to human intervention and manipulation in order to ensure a certain desired outcome.

<sup>13</sup> In the days before the easy availability of mass contraceptive measures, reproduction was often, if not invariably, the unintended outcome of sexual intercourse.

<sup>14</sup> Lesbian and gay couples have also resorted to such technological means of production to achieve parenthood. In 1996, two gay men in Edinburgh announced the birth of their daughter to friends. One of them, an American citizen, had used his sperms to fertilise eggs donated by a paid surrogate, a fellow American, who carried the pregnancy successfully. (See Mega, 1 September 1996.)

<sup>15</sup> See Kevles, 1995.

<sup>16</sup> See Keller, 1992, pp. 294–5.

<sup>17</sup> See Keller, *ibid.*

<sup>18</sup> See Keller, *ibid.*

<sup>19</sup> See Robert Sinsheimer wrote in 1969:

It is a new horizon in the history of man. Some may smile and may feel that this is but a new version of the old dream, of the perfection of man. It is that, but it is something more. The old dreams of the cultural perfecting of man were always sharply constrained by his inherent, inherited imperfections and limitations . . . To foster his better traits and to curb his worse by cultural means alone has always been, while clearly not impossible, in many instances most difficult . . . We now glimpse another route – the chance to ease the internal strains and heal the internal flaws directly, to carry on and consciously perfect far beyond our present vision this remarkable product of two billion years of evolution. (1969, pp. 8–13)

<sup>20</sup> Today, genetic clinics in some countries enable parents to choose the sex of their offspring. In north India, parents often choose to abort female fetuses (identified as such *via* amniocentesis or scan) for

cultural/social reasons. But ethics committees attached to hospitals and clinics in the mature industrial economies do not tolerate such a practice.

<sup>21</sup> On the ontological dimension raised by the subject of patenting transgenic organisms, as well as complete or partial DNA sequences, see Lee (2005, Chapter 5).

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# Moral Constraints on Permissible Genetic Design

Thomas Pogge

This paper takes a step beyond the enhancement debate, into the domain of genetic design. It explores what morality may have to say about the creation of “designer babies,” that is, about new human beings whose genetic code is either composed from scratch or produced through modification of a fertilized human egg cell or of a human clone. I pose this bewildering question in the context of an imagined future world in which genetic design is much more advanced in a way that makes it safe, predictable, and reasonably affordable. Such a future world may be less than a century away. I also impose three artificial limits on the discussion: I consider genetic design or redesign only in regard to a one-cell organism that, once designed, will grow and develop “naturally” without any further genetic interventions. I confine the discussion to the design of what clearly are human beings, that is, beings whose genetic endowments all lie within the parameters of the existing human gene pool. And I assume a social world much like ours, in which the creation of new human beings is initiated by human adults who generally love and care for the child and who bear a legal responsibility to safeguard the child’s basic interests until it reaches maturity. In such a world, I conclude, the law may be quite permissive with regard to the genetic design choices of parents.

## 1 Introduction

Recent years have seen a lively discussion in bioethics about the morality and wisdom of so-called enhancements. At issue in this discussion are enhancements of human beings through newly available chemical and biological (specifically genetic) means. The discussion is interesting and important, but it also shows that our new and rapidly expanding technological capacities have greatly outrun the range of our morality: the domain of moral reflection where we feel on firm ground and somewhat confident, at least, of the moral judgments we make and of the reasons

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T. Pogge

Professor of Political Science at the Columbia University, New York  
e-mail: tp6@columbia.edu

we adduce in their favor. A good part of the literature thus seems adrift. Even where strong positions are forcefully endorsed, there is generally a dearth of solid arguments in their favor. I am saying this not to criticize, but to highlight the interesting fact that morality, however *a priori* Kant thought it was, is fitted to the human world in which we live. If this world changes dramatically, as it has changed through the breath-taking advances of recent biology, we may lack not merely the sound judgment needed to apply our morality to new circumstances nor even moral intuitions that extend to the questions we face, but we may even lack the very concepts in terms of which the issues before us can be thought through from a moral point of view. This is a real problem. Biology does not wait for moral reflection to catch up. Crucial decisions about the use to which research results are being put and about the direction of future research are being made in real time – whether or not our moral thinkers are ready to pronounce upon these decisions.

This paper goes beyond this enhancement debate by considering the creation of new human beings whose genetic code is either composed from scratch or produced through modification of a fertilized human egg cell or of a human clone. In the first case – *design* – the genetic code of a human being is put together from various human (or perhaps even non-human genetic materials), creating the desired composition of genetic features and predispositions. In the second case – *redesign* – the genetic code of a human being is modified, at the very beginning of a human life, to produce the desired composition of genetic features and predispositions. Both cases exemplify genetic engineering applied at the very beginning of a new human life. And I believe, and will assume, that the two cases do not differ significantly, so that nothing is lost by discussing them under the common label *genetic design*.

This fundamental similarity between the two cases indicates how the terrain we are about to explore lies beyond enhancement which, as a matter of semantics, involves the idea of a triadic relation: the idea of something, A, that is being enhanced by B and thereby transformed into something else, A+. Such a transformation changes A, and in assessing this change one may then need to differentiate between evaluations one might make of this transformation from the potentially quite different standpoints of A, A+, and A' (the person A would have become if the enhancement had not taken place). This difficulty for the assessment of induced changes in a person's values and personality is the greater, the more fundamental this change is.<sup>1</sup>

The difficulty in discussing genetic design is qualitatively different and rather greater than that concerning enhancement. In cases of design, there is neither a pre-existing A that undergoes enhancement, nor is there some B, some enhancement that is being supplied. There is only a brand new one-cell human organism whose genetic materials accord with some human plan.

This is rather a remote problem for a conventional moral philosopher to think about. In trying to do so, we are imagining a future world in which genetic design is very much more advanced than it is at present, advanced in a way that makes it *safe, predictable, and reasonably affordable*. Such a future world may seem far off – but, measured in historical time, it may only be a blink of an eye away, probably no more than a century.

## 2 Limits on Discussion

Lest we lose our bearings completely, I will now impose three artificial limits on my discussion. I emphasize that these limits are wholly artificial – they do not exist in the real world, natural or social. Because of this, I will not be talking about the real world, but about a simplified model world. If you think that little is achieved by answering purely hypothetical moral questions that *would* arise in some model world, then you have my agreement. I concede that nothing I will say can claim definitive validity. Still, my hope is that my model will allow us to focus our thoughts and will help us gain a first approximation. If the model is well-constructed, then this first approximation, though not applicable to the real world, will get us a lot closer to a satisfactory treatment of real-world problems – of the problems we face now, when genetic engineering is still in its infancy, and of the problems we will face in the future when our genetic engineering capabilities will transcend the limits of my model world. The methodological idea behind my model world is then that the real-world problems we are and will be facing can be decomposed into two components by asking *first* how such questions are most plausibly answered in the model world and then, *second*, what difference the ways in which the real world is different from the model world make to the plausibility of the solutions I propose for the model world. We will have to ask again at the end whether this methodological idea has proved sound and fruitful.

Let me proceed to specify, then, the limits I impose to specify my model. Limit One is that I consider genetic design or redesign *only in regard to a one-cell organism* that, once designed, will grow and develop “naturally” without any further genetic interventions. This limit is significant in two ways. First, it supports my earlier assumption that there is no significant difference between genetic design and redesign. This assumption would evidently be implausible if more fully developed organisms were included in the discussion. The genetic redesign of a human person, the reader for example, raises obvious moral questions concerning the rights and interests of the person you now are. However, in redesigning a human being at the one-cell stage, such moral questions do not enter, except perhaps within certain religious world views. Outside such religious views, there is no serious question about whether the redesign accords with the rights and interests of the one-cell being that existed before the redesign – or so I believe. Those who disagree with this claim can restrict the following discussion even further, just to the design case: the case where a one-cell human being is created from scratch by, as it were, constructing its DNA through a free composition of genes.

The other significance of Limit One is that it prevents us from being immediately overwhelmed by deeply troubling questions concerning genetic redesign at later stages. This will allow us to think more clearly about the case at hand. But it also brings with it the danger that the conclusions we reach will not withstand obvious Sorites problems once Limit One is lifted.<sup>2</sup>

Limit Two is that I confine my discussion to the design of what clearly are human beings, that is, beings whose genetic endowments, at least for the most part, lie within the parameters of the existing human gene pool. By this I mean that most genetic traits and predispositions of such design creatures will lie within the range of

what human beings have exhibited before the genetic revolution – though designed beings, just like undesigned ones, may of course instantiate *combinations* of genetic traits and predispositions that have never existed before.<sup>3</sup>

By imposing Limit Two, I leave out of account the fact that, with genetic design in the picture, there will not be a clear and sharp distinction between human and non-human organisms and that the genetic design possibilities will then seamlessly extend across the whole range of conceivable living organisms. Some of the possibilities here are comparatively harmless: We may go beyond the parameters of the human gene pool by using a gene that developed in the evolution of mice or tomatoes in order to increase the disease resistance of the otherwise wholly human embryos we create. But there are much, much more dramatic possibilities within the full space of living organisms we may come to be able to create. Some of these organisms may have an intellectual and emotional life that clearly qualifies them as persons, even though they may look more like birds or fish. Some, though perhaps human in appearance, may have vastly greater natural endowments than any human beings have had heretofore and, once fully grown, they will then vastly outperform presently existing humans in terms of physical and mental powers, longevity, and disease resistance. Limit Two excludes these possibilities from the discussion, but the latter ones, especially, are obviously pertinent: If parents are legally permitted to design their child so that some of its genetic endowments are at the top of the human range, then why should they not be permitted to go a little over the top, or even a lot over the top? So Limit Two, as well, is accompanied by the danger that the conclusions we reach will be undermined by Sorites problems.

Limit Two excludes not only non-human and superhuman persons from consideration, but also organisms that fall below the threshold of personhood. Obviously, the genetic design capabilities now under development will soon make it possible to design living beings that are in various ways intermediate between human beings and other now existing animal species, and these possibilities will put great pressure on our concept of a person. Think of the famous dystopian novel *Brave New World*, by Aldous Huxley, which envisaged the design of borderline human beings, the Deltas, who were used for menial tasks. This is no longer a far-fetched scenario. Once our legal definition of personhood has been more sharply defined in response to the new genetic-design possibilities, there is bound to be commercial interest in designing beings just below the threshold of personhood (as defined), who can be bought and sold like animals but are much better than animals at cleaning our houses, driving our cars, and doing all sorts of other menial chores. Of course, non-organic robots can also do many of these things, but it may be emotionally more satisfying to deal with a designer pet than with a robot. Such designer animals – I call them animals because they would fall outside the then prevailing legal definition of a person – might come in all shapes and sizes. Some intelligent enough to do various tasks, along the lines of the dolphins that are now being trained by the US navy for mine clearing duties; some human in physical shape to fulfill human aesthetic preferences and sexual needs; and so on. Nauseating thoughts – but such possibilities now look like they will be technically within reach in the foreseeable future. Leaving these thoughts and possibilities aside again makes it easier to think soberly and clearly

about our topic. But the price, once more, is that our conclusions may have to be revised once the limit is lifted (as eventually it must be).

Limit Three is the assumption of a social world much like ours, in which the creation of any new human beings is initiated by human adults who generally love and care for the child and who bear a legal responsibility to safeguard the child's basic interests until it reaches maturity. There is no assurance at all that the future will be like this. Once human beings can be genetically designed and presumably also grown outside a female body, all sorts of human agents and agencies may wish to get into the child rearing business. Some governments may wish to design their future military personnel, for example, people whose capability and preference profile matches that of a fighter pilot or special-forces operative. With luck, persons so designed will still have the legal freedom to go into other lines of work. But they will be predisposed to be best suited and happiest with a career in the military, and most of them will then end up there. Once governments develop such programs, corporations, universities, and hospitals may not be far behind. They too may well be eager to design and raise persons for various specialist jobs, thereby ensuring an ample supply of job occupants. Even if the people raised by such an agency would later decide to work for a competitor, the agency would still benefit indirectly: Once there are many people capable of being top-notch brain surgeons, rocket scientists, or corporate chief executives, then the salary for such people could be much lower than it is now, resulting in large payroll savings to all hospitals, universities and corporations that employ them. Leaving these rather realistic scenarios to one side, I conceive my model world to be one in which only private individuals bring new human beings into existence – with the help of genetic engineering, if they so choose.

By incorporating the three limits I have specified, my model world would be much like ours, except that it would be technically feasible for parents to have the legally protected freedom to design their own children within the general parameters of the human gene pool. Parents could have the child of their choice, at least as far as its genes are concerned. This is a fantastic expansion of the freedom of ordinary people, even if (as we shall see) it may reasonably come with various limitations. Whereas in the past parents could only accept (or perhaps reject) what they were given by the “natural lottery,” in the model world parents will be able to choose among billions of design combinations. Even if they lose the legal freedom to let their child's endowments be determined by the natural lottery,<sup>4</sup> this transformation does bring a huge net gain in procreative freedom, which creates a strong presumption in favor of permissive legislation: Adults can truly procreate, rather than merely reproduce. This presumption is supported by the very core of liberalism: The state ought not to restrict the freedom of its adult citizens without a good reason. And the presumption is also plausible on policy grounds. Nearly all parents care about the best interests of their children and want them to grow into happy, productive and successful adults. Here the concerns of parents are naturally aligned with those of society, with our collective interest that those who come after us shall grow into happy, productive and successful adults. So it seems that the expanded procreative freedom not only greatly benefits those who enjoy it but also – unlike many other more familiar freedoms – confers substantial positive externalities upon others.

Within the model world defined by my three constraints, what could possibly be wrong with legislating the most extensive procreative freedom, which lets every couple choose the genetic endowments of its child within the parameters of the human gene pool?

The answer is: A lot. There are many objections to such unfettered procreative freedom. These objections fall into two broad categories: General objections to any and all genetic design services.<sup>5</sup> And more specific objections to the availability of some specific genetic design choice or narrow class of such design choices. I will address these two categories in this order.

### 3 Objections to Genetic Design

1a) One worry that has often been expressed with respect to genetic enhancement also applies here to genetic design. This general worry is that a market in genetic endowments would aggravate existing inequalities, because the poor would be unable to afford genetic design services or at least the more valued ones. I suspect, however, that once genetic design technologies will be safe and effective, their large-scale use will also be reasonably cheap. My interest here, in any case, is with the more fundamental ethical issues, and so I will assume that all couples, regardless of income, will be entitled to genetic design services (including genetic counseling), free of charge, for the production of at least two children. On this assumption, genetic design does not aggravate inequalities but rather functions as an equalizer. In present societies, the perceived value of persons' natural endowments is highly correlated both with their socioeconomic status<sup>6</sup> and with the perceived value of the natural endowments of their offspring.<sup>7</sup> These two correlations, linked transitively, as it were, produce a pretty strong correlation between the perceived value of persons' natural endowments and parental socio-economic status: The children of the rich and mighty tend to be better endowed than the children of the poor and powerless. Universal access to genetic design services would redress this intergenerational transmission of inequality, giving poor couples the same access the rich enjoy to the full range of available genetic endowments for their children. Legitimate concerns about the intergenerational transmission of inequality thus do not merely *fail to oppose* the extension of procreative freedom to genetic design, but positively *support* such an extension. Thus, assuming universal access to the technology, the first general objection reveals itself to be a boomerang: Far from counting against full procreative freedom, egalitarian concerns actually count in its favor.

1b) Another often-voiced general concern is that deliberate genetic interventions would alter the human gene pool. To be sure, given the way my model has been delimited, such interventions would not change the basic parameters of the human gene pool. But they might well dramatically shift, and also concentrate, the prevailing frequency distribution, greatly reducing, for example, the incidence of deafness, baldness, melancholy, near-sightedness, obesity, poor memory, and low native intelligence. Such a shift may seem problematic insofar as it would reduce

human diversity and might even root out various unpopular genetic traits from the human population. However, this problem is more apparent than real. Rooting out various unpopular genetic traits from the human population is not really problematic because, with genetic design technology on hand, these traits could always be reintroduced should they ever turn out to have some heretofore unappreciated benefit. In the model world, the distinction between somatic and germline genetic interventions – prominent in the essays collected in *From Chance to Choice*<sup>8</sup> – would lose nearly all of its significance. There would be no loss in the diversity of available human genetic materials. To be sure, there might well be a loss in *manifested* human genetic diversity. But why should this be considered a cost? Suppose that, under conditions of full procreative freedom (within the limits of my model), many traits would never or almost never be chosen because they are widely perceived as inferior or as handicapping or simply as unfashionable. Why should the absence of these traits from the human population be regretted when people actually do not wish to choose them for their children? And, if it is regretted, would it really be alright legally to require some couples to raise children with genetic traits that are widely regarded as undesirable just so the rest can enjoy some extra diversity? Again, I find no merit at all in the second general objection.

1c) A third general objection<sup>9</sup> against permitting genetic enhancements, invokes the principle that a decision about the genetic endowment of another human being is permissible only insofar as the consent to the future person whose endowments the decision affects can be anticipated beyond a reasonable doubt. This principle is underspecified insofar as it leaves open *which* future self or selves must endorse the decision – for example, the person at age 18, at age 42, at age 60, at *most* mature ages, or what? Moreover, any such principle strikes me as unreasonably restrictive. Parents may well be faced with choices such that *any* decision they make will run a risk of later non-endorsement. This is clearly true of many non-genetic choices parents face with regard to their children. For example, parents face the choice which language shall be their child's first or native language. No decision they might make – including, of course, the decision of having their child grow up without any language at all—can pass the analog to Siep's test. My reply to Siep shows that his objection is ultimately dependent on another general objection that he also advances and that I discuss next.

1d) This fourth general objection invokes a distinction between the natural and the artificial. Equipped with this distinction, Siep restricts the applicability of his future-endorsement principle to genetic engineering, exempting both non-genetic decisions (such as that about a child's first language) and "natural" procreation through traditional sexual reproduction. Consider how such an asymmetrically applied principle would work in practice. Imagine a couple both of whom are genetically predisposed toward obesity. Their decision, or that of their society, that their predisposition is to be passed on to their offspring counts as "natural" and hence is exempt from Siep's principle. Their decision *not* to pass on this gene, however, *is* subject to Siep's principle. So even if it is *very likely* (though not certain beyond a reasonable doubt) that their future offspring, whether predisposed to obesity or not, will much prefer not to have this predisposition, still Siep's principle counsels in

favor of obesity. This shows that, appearances notwithstanding, Siep is not really concerned for the best interests of the couple's future children, for whether they can come freely to endorse their genetic traits. Ultimately, what becomes decisive in Siep's account is not deference to what future persons will endorse, but his own sense of what is natural and what is artificial.

This distinction, of course, is not an easy one either to draw or to show the moral significance of. Siep writes: "the value of the natural process of reproduction consists partly in saving us from the responsibility to technically control the process and products of human reproduction."<sup>10</sup> "The concept of the natural as 'species-typical normal functioning' is an evaluative concept of nature and the natural. . . . If it is abandoned, society itself becomes responsible for designing and distributing the genetic conditions for human well-being. Here as in other instances nature relieves society of the responsibility for the distribution of capacities."<sup>11</sup> There are two things wrong in this passage. First, genetic design may, and in my model will *not* transgress the bounds of species-typical normal functioning, which includes both the predisposition toward obesity as well as the absence of this predisposition. There is nothing unnatural about lacking the genetic predisposition toward obesity – the only "unnatural" element is the *means* the parents use to liberate their children from this predisposition. Second, it is unclear how a decision *not* to use certain available technologies can relieve the decision maker of responsibility. Siep's argument here has a strong resemblance to arguments presented by Jehovah's witnesses, who claim that the decision to *deny* medical treatment to sick people relieves one of responsibility for their fate while the decision to *provide* such treatment renders one responsible. I am sure Siep would not want to endorse such parallel arguments. But how can he avoid doing so? Offhand, it seems that letting a person's genes be determined by a lottery rather than by her parents is no more natural than letting a child die of a bacterial infection that could be cured with antibiotics.

e) Closely related to this last point is a fifth general objection which opposes genetic engineering on the ground that it is tantamount to "playing God." This argument runs into the same twin problems: It is in danger of showing too much: Does trying to save the life of an accident victim also amount to playing God? And it has trouble explaining why the decision *not* to use certain available means does not also involve playing God: Are we not playing God when we deliberately deny obese couples the freedom – enjoyed by most other couples – to produce children who are *not* handicapped by a predisposition toward obesity?

I cannot be sure that I have considered all popular or plausible general objections to genetic design, and so I can conclude only tentatively and for the time being that there are no convincing *general* objections to genetic design in the model world. So let us now look at *specific* objections – objections to the availability of some specific genetic design choice or narrow class of such design choices.

To prepare the ground for such objections, let me categorize the various kinds of human features that are likely to be conditioned or influenced by genetic endowment. Without claiming completeness, we might differentiate among genetic traits on the basis of the features they predispose their bearers to have. Using this

organizing principle, we might distinguish – going from the more straightforward to the more complex and difficult – genetic predispositions

- toward sex/gender,
- toward skin color,
- toward perceptual capacities (for sight, hearing, taste and smell),
- toward physical abilities and disabilities (height, strength, dexterity, stamina, longevity, disease resistance),
- toward appealing physical features (facial features, eye and hair color, posture, double eyelids, straight teeth, etc.),
- toward mental abilities and disabilities (memory, intelligence, concentration, reaction time, etc.),
- toward emotions (cheerfulness, anger, melancholy, etc.),
- toward conduct (aggressiveness, altruism, gregariousness, homosexuality, etc.)
- toward other character traits (autonomy, docility/rebelliousness, attachment and bonding, sense of humor, etc.).

Let me begin with a rather straightforward set of such features: genetic predispositions toward perceptual acuity or what I simply call “perceptual endowments.” Some people are better at seeing (without glasses), hearing, tasting and smelling than others are, and some retain their perceptual discernment capacities longer into old age than others do. These interpersonal differences are certainly in part genetically based. And we can expect then that parents would choose to design their children to be endowed for perceptual capacities at the top of the human range. Apart from a temporary oversupply of medical specialists (in the business of correcting for perceptual deficiencies) and a temporary oversupply of cheap wines (which only the taste-impaired would ever drink), this rush to secure top perceptual endowments for one’s children does not seem to pose any moral problem at all. – Or does it?

One argument against legalizing the creation of human beings with top perceptual endowments is that this demeans the rest of us, those who are already living with perceptual endowments of the presently more ordinary kind. We folks with middling endowments can say that, if prospective parents are allowed to choose better perceptual endowments for their children than we possess, and if most of them actually choose to do this, then they are sending a message to us that lives with perceptual faculties like ours are less worthwhile and that it would have been better for us to have been conceived with top perceptual endowments – or rather, it would have been better for humans with top perceptual endowments to have been conceived in our stead – if only that had already been possible when we were born. Because it would be wrong to send such a message to us, prospective parents should not have the legal freedom to choose top perceptual endowments for their offspring.

I do not find this a promising argument, for three reasons. First, the message those prospective parents are supposedly sending to us seems plainly true in a sense: Other things being equal, persons are better off with keener sense perception. Second, even if such a message were not plainly true, but rather subject to reasonable disagreement, those parents would still do us no wrong by being on

one side rather than the other of this disagreement. They certainly do not wrong us badly enough to justify legal restraint. Our discomfort with their judgment is not sufficient reason for legally preventing them from acting on their judgment. To see this more clearly, consider a parallel case: Parents who buy braces for straightening the teeth of their child thereby “send a message” that, other things being equal, their child is better off with straight teeth. Older persons with crooked teeth (which, at our age, are beyond correction), may take offense at this. But surely we would be way out of bounds if we demanded that the state should outlaw such cosmetic treatments.

My third reason against accepting this argument is a negative one. Consider what things would be like if the argument went through. Should perceptual endowments then have to be settled through conventional sexual reproduction? In this case the well-endowed would have the opportunity to produce offspring with top perceptual endowments while the rest of us would avoidably be denied this opportunity. This would unfairly compound genetic inequalities, as the best-endowed would in addition also have the best-endowed children. To be sure, this has been the way of the world throughout all of history. But now, when this unfairness becomes remediable, I see no reason why we should continue to accept it. To be sure, we could avoid the unfairness by forcing the same middling perceptual endowments upon *all* prospective parents and their children. Or we could institute some lottery scheme that randomly assigns top, middling, and poor perceptual endowments to prospective parents, in rough proportion perhaps to the shares such endowments now have in the human population. But these options are deeply unattractive as well, because they are collectively irrational and moreover would deny the perceptually well-endowed the right to choose conventional sexual reproduction.

Taking all three reasons together, I conclude that the so-called expressivist argument fails for perceptual endowments. Procreative freedom may not be legally restricted with regard to perceptual endowments on the ground that prospective parents would or might choose to send an unwelcome message by not choosing some of the traits instantiated in presently living persons.

Let me inject an observation about my argumentative strategy here. The expressivist argument is usually presented and discussed in reference to rare special traits associated with what we now call impairments, disabilities, or handicaps. I think the argument can be satisfactorily answered in this context.<sup>12</sup> But I also believe that the somewhat more futuristic context of my model world confirms and strengthens that answer. In the context of the model world, all of us alive today are multiply impaired, disabled, and handicapped. Each of us has dozens of genetic features that sane parents would not want to choose in the genetic design of their offspring. Some of us are predisposed to early balding, some to crooked teeth or poor posture, some to obesity, some to melancholy, some to catching colds or other diseases, some to forgetfulness, some to sexual dysfunction, some to shortness of life or stature, some to low intelligence or concentration, and so on and so forth. Saying clearly how multiply defective we all are takes the sting out of the charge that the move toward genetic design is somehow discriminatory. This move does not endanger the continued existence of people like *those* – pointing to some small groups of the blind, deaf,

paraplegic, sickly and retarded. Rather, this move threatens the continued existence of people like *all of us* – people with many genetic impairments and imperfections.

Still, what I have just said should be balanced by conceding that the expressivist argument has greater force when it is marshaled in opposition of free choice by parents of the sex or skin color of their children when it is known that such choice would run heavily against some particular sex or color. Suppose that, given such free choice, three quarters of all children conceived in India would be boys. Would this not be a terrible insult to Indian women? I think it may well be such an insult. But I am much less sure that such choice, or the present practice of selective abortion, should therefore be outlawed. My reasons for skepticism are, first, that such legal restriction would suppress a symptom rather than cure the disease: the great sexism still prevalent in the Indian culture manifesting itself in the financial hardship daughters bring to the family, especially through dowry expenses. And, secondly, such a skewed birth ratio of 3:1 in favor of males is likely to help correct this sexism. Would the practice of expecting the parents of young women to pay a substantial dowry for the privilege of getting their daughter married off into another family – would this practice really endure when two thirds of all males are destined to remain without a wife?

Or consider next the case of skin color. Suppose that, in some society, blackness is widely considered loathsome so that a substantial proportion even of blacks would choose whiteness for their children or at least a lighter skin color than they themselves possess. Again, such a pattern of choice would be insulting to blacks and, in contrast to the case of sex, might actually extinguish this color in the society in question. And yet, I think that even here the reasons against restricting choice have considerable force. Outlawing such choices would, once again, suppress a symptom rather than the disease of racism. And it would also run into the problem we have already discussed in the case of perceptual endowments, the problem of allocating the perceived burden of raising black offspring. Should this burden be imposed upon unwilling blacks, who then would not only live in a racist society biased against them but would also be required, as a condition of procreating at all, to accept black offspring even while everyone else would be free to have children in the color they prefer? Or should the burden be randomly distributed so that every prospective couple would have to accept a certain probability of their child being designed to be black?<sup>13</sup>

This concludes my observation about the argumentative strategy I have sketched in regard to expressivist arguments, and I return now to the main line of my discussion. Parents should be legally *permitted*, I have argued, to choose top perceptual endowments for their children. But should they also be legally *required* to do so? What if some parents do not want to follow the herd and want deliberately to give their offspring lesser genetic endowments for excellent and enduring perception? In the context of my model world, such choices seem very hard to justify – indeed, such choices may seem perverse. Why should parents be allowed to design their children to have poor eyesight or bad hearing in old age? To be sure, such genetic predisposition may not greatly affect a person's quality of life – certainly nowadays when various gadgets and remedies are readily available – and people have

lived with them for all of human history. Still, even if the impairments are of minor significance for most people, why should parents be allowed to inflict them on their children?

Well, here is one reason. Prospective parents may want to reproduce in the conventional way, without genetic engineering, leaving their children's endowments to the "natural lottery" as Rawls has memorably called it. They may want to do so on broadly nostalgic grounds, in solidarity or kinship with all the human generations that have gone before. Or they may do so on some religious grounds. Either way, there is certainly a presumption that such a decision ought to be legally permissible.

But would not the children of such parents be seriously disadvantaged, especially when most of their peers enjoy top perceptual endowments? In the case of perception, the actual disabilities such persons will encounter may not be grave. Perhaps all they will need is a pair of glasses and, later in life, a hearing aid – minor inconveniences. But there may be additional social disadvantages in living as an obviously undesigned human being in a society in which others were designed by their parents with tender loving care. These disadvantages are very hard to predict; and the greater they are, the more reason there would be to outlaw conventional reproduction when it would result in obviously inferior endowments. These reasons may still not seem very strong in the case of perceptual endowments – but they become much more compelling as we include other kinds of endowments in our investigation. For now, let me just flag three further points:

The reasons *against* outlawing conventional reproduction for certain couples in the model world are certainly weaker than the reasons against outlawing such reproduction for certain couples in the world as it is. This is so because, in the model world, people could still procreate through genetic design – and could even come close to reproduction by availing themselves of genetic *redesign* that merely makes the changes minimally necessary to avoid serious disadvantage to their child. In the model world, absolutely every adult has the opportunity to procreate. But what about persons who recognize a religious duty not to procreate except in the conventional way?

The reasons *in favor of* outlawing conventional reproduction for certain couples in the model world are also weaker than the reasons in favor of outlawing such reproduction for certain couples in the world as it is. This is so because the model world is likely to be very much more advanced than ours also in regard to the correction of genetically-based impairments. Poor eyesight can already be corrected through laser surgery; and so in this case very little harm seems to result from permitting parents with poor eyesight to reproduce. Insofar as many other perceptual impairments – even blindness or deafness – will be easily correctable in the model world, the reasons against permitting the birth of human beings predisposed toward such impairments weaken or disappear completely.

There may be no reason, in my model world, to outlaw conventional reproduction by couples that themselves consist of (former) designer babies, assuming such couples would be certain, or at least very likely, to produce offspring at the top of the human endowment range. This point may seem to make legal restrictions on conventional reproduction more tolerable, because they affect an ever shrinking

number of adults. But it may also sharpen the unfairness inflicted on the remaining couples who are barred from conventional reproduction when most others are not.

## 4 Conclusion

To conclude, I have here been able to give you merely a taste of what will be a much longer paper which, I hope, will be better informed of what is now known about genetics, will deal with many more kinds of genetic endowments and predispositions, and will also consider many more arguments for and against freedom of genetic design. Let me state once more, concisely, the point of the exercise as I see it. In thinking about how to legislate in the face of the dramatic new genetic design and redesign possibilities, we must try to anticipate how these possibilities will expand in the future. I have here anticipated a future world with vast design possibilities that, for all I know, may transcend what will in fact ever be possible. I have tried to set some moral markers for such a world that may help us orient ourselves in the world we will inhabit in the next few decades. In setting these markers, I have imposed three artificial limits on my discussion, thereby defining a highly artificial model world that is much easier to think about than the distant future that humankind – or should I more cautiously say: “our progeny” or “those who come after us” – will actually face. My hope was that this model world, though wholly unrealistic both scientifically and socially, can nonetheless help us think about the distant (and hence also about the proximate) future by raising fruitful questions of the form: What difference do the ways in which the distant future will be different from the model world make to the plausibility of the solutions I propose for the model world?

## Notes

<sup>1</sup> Consider, for instance, a person who is put on a mood-enhancing drug, such as Prozac, which suppresses certain dark existential broodings. It is possible that this person becomes a well-adjusted citizen who considers the absence of such moods of existential despair to be a blessing – even while both her earlier self and the later self she would have become but for the administration of Prozac would have, at least when in one of the existential moods, considered a life without deep and painful existential insight to be a complete waste.

<sup>2</sup> A Sorites problem emerges when we believe that any moral judgments we make with respect to a one-cell organism must also hold with respect to a two-cell organism and that any moral judgments we make with respect to a two-cell organism must also hold with respect to a four-cell organism and so forth, producing a chain that undermines our judgments regarding one-cell organisms by showing such organisms not to be sharply distinct from human persons.

<sup>3</sup> Simply put, one may think of each genetic endowment as a unique point in a very high-dimensional space of possibilities. Such a genetic endowment falls within the parameters of the existing human gene pool if and only if, in each and every dimension, it falls between the previous observed extremes. I allow small departures from this stipulation, involving perhaps superhuman eyesight or superhuman resistance to a certain disease. Even those who have such special traits would still blend in quite well with a population of human beings whose genetic endowments lie within the parameters of the existing human gene pool.

<sup>4</sup> More on this below.

<sup>5</sup> Such general objections sometimes exempt genetic design services that merely help avoid a narrow class of genetic defects and hereditary diseases.

<sup>6</sup> This is so because valued endowments bring social success.

<sup>7</sup> This is so because better endowed and therefore probably socially more successful persons tend to marry one another and then to have children who inherit their superior natural endowments from them.

<sup>8</sup> Buchanan, Brock, Daniels and Wikler 2000, e.g., 159.

<sup>9</sup> Cf. Siep, 194.

<sup>10</sup> Siep, 201.

<sup>11</sup> Siep, 197.

<sup>12</sup> Cf., e.g., Buchanan, Brock, Daniels and Wikler 2000, Chapter 7.

<sup>13</sup> And would couples losing the lottery then have the option to back out: to remain childless so as to avoid having a black child?

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