DISSERTATIONES PHILOSOPHICAE UNIVERSITATIS TARTUENSIS

4

DISSERTATIONES PHILOSOPHICAE UNIVERSITATIS TARTUENSIS
4

BENEFIT-SHARING: AN INQUIRY INTO JUSTIFICATION

KADRI SIMM

TARTU UNIVERSITY
PRESS

Dissertation has been accepted for defense of the degree of Doctor of Philosophy (PhD) in Philosophy on September 29th, 2005 by the Doctoral Committee of the Board of the Department of Philosophy, University of Tartu.

Supervisors: Professor Margit Sutrop, University of Tartu
Dr. Tuija Takala, University of Manchester and University of Helsinki

Opponent: Professor Ruth Chadwick, University of Lancaster

Defence: November 21st, 2005

ISSN 1406–1058
ISBN 9949–11–167–6 (trükis)
ISBN 9949–11–166–8 (PDF)

Tartu Ülikooli Kirjastus
www.tyk.ee
Tellimus nr. 445

CONTENTS

INTRODUCTION

This work focuses on the question of benefit-sharing in biomedicine, especially within human genetic research. More precisely, I will be examining arguments that can be used in justifying why benefits resulting from human genetic research should be shared. Benefit-sharing in human genetics is well established in documents and rhetoric but systematic analysis of the reasoning and justification of this concept is often lacking. Besides analysis of the lines of reasoning behind calls for benefit-sharing, my aim has been the general clarification of the concept. First applied within agricultural research, later coupled with the compensatory logic of medical trials, benefit-sharing is a complex notion increasingly employed to further claims of justice and fairness also on global scale.

Why benefit-sharing? Benefit-sharing pertains to the distribution of benefits but also of burdens arising from the research and development activities in human genetics. It concerns the issue of what is owed to those people participating in research but also to those who might not have taken part personally but live in the same community or even population where research is undertaken. Results arising from research can span a wide array of potential benefits and burdens from improved drugs and therapies to preventive and personalised medicine, to name only a few potentialities from the health care sector. Furthermore, human genetics is part of a large technological development with universal impact and this raises concerns regarding the accessibility and availability of the results of research also on a much wider, global scale thus shifting the entire issue from the sphere of medical ethics to that of global justice.

Why human genetics? The Human Genome Project and the related activities in biomedicine and -technology have raised many important and rather burning social, ethical, economic, political and other issues. Human genetics is the source of many expectations for decreasing human suffering and transforming much of traditional medicine in diagnosing, curing and preventing illnesses. Human genetic research has also been the subject of speculations regarding our potential ability to influence or even design the future of mankind.

Simultaneously with heightened hopes for cures and various enhancements, fears have been expressed regarding the immense potential for harm that genetic information might hold. Naturally, scientists have pointed out that genes and the information embedded in these are only one side of the picture where human being is concerned. The factors ranging from nutrition to education, as well as gene-environment interactions are very significant in moulding a person — a fact that has been somewhat lost in the relevant media discussions. I should like to make it clear though, that my focus in terms of benefit-sharing will be on health-related and financial benefits mostly, leaving aside the controversies of new improved human species and the like[1]. Perhaps this is a somewhat short-termed emphasis in comparison with the potential of large scale gene manipulations and the similar future possibilities[2].

Human genetics provides an interesting intersection of many fields of human activity. It has outgrown the traditional confines of medical research as most of investment is now originating from the private for-profit sector. For example, while the rationale behind setting research priorities involves the betterment of human health, the actual funding decisions are based on calculations that line up these competing possible future projects in terms of their potential to create revenue. The scale of research, like the Human Genome Project that strives to map the human genome, is truly global. Politics and history also play an important role as colonisation experience, issues of power and powerlessness and the stark inequalities of the present world need to be negotiated and assessed. Indeed, one of the most important distinctions I insist on in clarifying benefit-sharing conceptually is the differentiation between two major levels in the application and justification of this notion. While benefit-sharing within specific research projects has traditionally been governed through principles from medical ethics (starting from informed consent to compensation for accepting certain risks), the very scale and scope of human genetic research has introduced new concerns for fairness and justice that call for a different justification for the entire notion. Fairness and various justice-related concepts are notoriously difficult to agree on, and the complex nature of genetic information complicates the application of this concept in benefit-sharing further. For instance, whose concerns are to be taken as relevant? In small-scale clinical trials or research projects this is easier to assess compared to large population-based genetic databases, where significant social concerns might arise.

I will draw attention to the way justifying arguments for benefit-sharing determine the composition of recipients to be shared with. In other words, certain justifications necessarily exclude or include specific groups or communities. For example, when we consider the genome to be a common property of humanity, the sharing should be done among all human beings. On the other hand, when benefit-sharing is conceptualised as a compensation for voluntarily taken risks, it would seem unfair to share benefits with those who have not taken any. Some of the uncertainties and doubts that have accompanied the benefit-sharing discussion in human genetic research might have to do with the

---

[1] Although I admit that it is difficult to draw a line between technologies, some of which might provide means of achieving also these rather fantastic-sounding and morally problematic results. Many so-called slippery slope arguments refer to the same problem, where initially ethically unproblematic technology might later be engaged with the rather more distressing applications.

[2] For an interesting discussion of the latter see Allen Buchanan et al., *From Chance to Choice: genetics and justice* (Cambridge: Cambridge University Press, 2001).

fact that certain justificatory arguments are not efficient in including the interests of relevant populations. Furthermore, different justifications can be contradictory and the employment of those competing concerns can complicate the issue further.

While benefit-sharing can be explained through a number of justifications, a major distinction I will argue for and will be utilising throughout the work pertains to a differentiation between sharing with those who have directly participated in research (and their close relatives or community) and a much wider perspective that concerns the availability of results of genetic research on the global scale. Traditionally biomedical research has been concerned with the sharing of benefits as regards the first group of people, those more or less directly involved. The practice of benefit-sharing, especially in agriculture, has introduced a different perspective that recognises the contributions of communities and populations. The issue is further complicated in human genetics as genetic information is by nature shared, thus involving individuals and communities who might not have participated in research in the traditional sense. Research is increasingly associated with for-profit companies and practices and other aspects of this large scale venture have given credence to concerns of political, social and economic origin. Of course, in principle "genetic research on global scale" is still made up of specific research projects but calls for benefit-sharing in universal sense ask us to look beyond these specific projects and assess the impact of the entire phenomenon inclusive of factors outside the regulated medical sphere. It is like taking stock of the ocean instead of focusing on the drops of water making it up.

In this work, I will focus on how benefit-sharing in human genetics can be explained, or more precisely, justified. Why should benefit-sharing be undertaken? Is it a duty or an act of charity? What is the reasoning behind calls for benefit-sharing? It is a complex but also rather ambiguous issue that has been much discussed but not systematically so. It is increasingly present rhetorically and forms an important part of most research projects nowadays as benefit-sharing schemes need to be outlined and even negotiated before research itself is begun. My aim in this work is to analyse the most relevant rationales for benefit-sharing, based on an analysis of available international documents and policy papers, as well as making use of the applicable reasonings within moral and political philosophy.

The first chapter will introduce the subject matter of benefit-sharing. I will start descriptively, drawing on major international documents and declarations that have referred to the necessity of sharing the benefits of various research and development activities. However, apart from a few exceptions, benefit-sharing is not usually explained or justified in these documents. I will then go on to draw and explicate an important distinction between specific and universal benefit-sharing frameworks. Also, I will clarify and categorise the content of the notion of benefit in more precise terms — what are these possible benefits to be shared? The chapter will end with an overview of arguments against benefit-sharing, which I will refute.

The next three chapters will each deal with one possible line of argumentation for justifying benefit-sharing. The solidarity, consequentialist and rights-based arguments are often used in debates and I will assess each of them separately. The focus on solidarity and rights discourse is based on an understanding that these concepts have been employed within debates on benefit-sharing and therefore it is necessary to examine them closely also from a prescriptive point of view. Although the consequentialist approach has not been so favoured in present discussions on benefit-sharing within biomedicine, in the context of global concerns it has been a prominent argument since the much publicised large-scale famines of the 1970s-1980s. At the same time I have not aimed at excluding other possible lines of justification.

Firstly, I will analyse the concept of solidarity as a possible framework for benefit-sharing. Solidarity is frequently employed rhetorically but the precise content of the notion is often left unexplained. This chapter is not centred on one theory but examines the concept of solidarity through the lens of various theoretical approaches. While communitarianism is most often associated with solidarity, there exist competing definitions and I will argue for a certain compromise between the liberal contractual and communitarian versions for a useful application in benefit-sharing debates. Additionally, I will draw attention to a close association between concepts of solidarity and justice, allowing concerns to be voiced in either of these sometimes competing, sometimes complementary discourses.

In the chapter theoretically grounded in consequentialism, I will examine the strengths and weaknesses of this approach in benefit-sharing context. I will focus on the argument that stresses our duty to avoid bad consequences. Could benefit-sharing be justified based on this rather stringent moral rule? This principle is certainly demanding because we are always in a position to avoid some future harm and if so, are there any limits to our responsibilities? Consequentialist argumentation has been previously employed in providing moral guidance to problems of global scale and I will borrow Peter Singer's negative utilitarian argumentation originating from the famine discussions of the 1970s-1980s and analyse its relevance in the present context of calls for universal sharing of benefits arising from human genetic research.

Thirdly I will examine the relevance of rights in this debate. Rights are a very influential moral and political concept. Claims dressed as (human) rights have universal appeal and they are thus a powerful argumentation tool in providing a more or less shared vocabulary, compared with, for example discourses on needs or justice. While I will not argue for a specific right to benefit-sharing as such, I will examine a possibility of conceptualising the issue in terms of the right to health care. Health care is relevant in this discussion because human genetics is primarily associated with benefits pertaining to human health and well-being. After a general examination of rights in philosophical discourse I will scrutinise the arguments for and against positive rights since the right to health care certainly qualifies as positive. My focus will be on arguing for the moral significance of health care through the accounts of Norman Daniels (theory of just health care that reasons through concepts like normal species-typical functioning and opportunity-range in a society) and Amartya Sen and Martha Nussbaum (functionings/capabilities account). Application of rights discourse in benefit-sharing is assessed lastly. While I have chosen the right to health care as relevant in benefit-sharing, this does not in principle exclude the possibility of employing other rights, as long as their enforcement is associated with the overall objectives of benefit-sharing.

I do not intend to claim that my chosen argumentative approaches exhaust the possible justificatory routes to benefit-sharing. Furthermore, rights-based theory does not exclude the relevance of outcomes or the importance of solidarity. Benefit-sharing is a complex subject matter and concern where various justifications might co-exist (and thus be complementary, although they can also be contradictory). Despite the differences in stress, explanations and conclusions among the competing discourses, there is a recognised and largely shared basis for claims being made on behalf of morality. In a way, all of these theoretical approaches have their sources in the murky primordial blend of human interests, needs, values, vulnerabilities, capabilities and other characteristics of the human condition. Regardless of whether the argumentation rests on the consequentialist, rights-based or some other line of thinking, reasoning "by default" starts from this more or less shared premise that these human qualities are morally relevant. Why they are accorded such importance might differ, as surely differs the right course of action to respond to them. But on some level the convergence of otherwise conflicting views should be celebrated.

I would also like to clarify the level of argument this work is written on and its methodology. Despite my basis in practical philosophy this is not a discipline-based nor a theory-centered study but a problem-based one. I will attempt to use the rich source of philosophy to seek elaboration and justification for the idea of benefit-sharing and since the topic itself is so complex, involving not only ethical but also political, social, legal and economic aspects, I have included relevant knowledge from other disciplines. Bioethics is an interdisciplinary field that has attempted to embrace important insights from moral philosophy, medicine, law and other related fields. Medical anthropology and sociology of health and illness are pertinent areas as the major contributions from human genetics apply to health care and medicine. Development studies engage not only with the economic aspects of poverty and global inequalities but also with the social, political and cultural issues around human development.

Many of the various justifications for benefit-sharing arise from diverse perspectives in moral and political philosophy. This also means that I will be employing a number of concepts that have inspired whole treatises devoted to their very definition and substance. Both theories (for example consequentialism) as well as the concepts utilised (e.g. solidarity) are very complex and have been developed in competing and sometimes even contradictory directions. Therefore, in order to engage a number of these relevant sources, I will hardly devote space and time for the justification, clarification and elaboration of theories of ethics *per se*. My aim is not, for example, to disprove consequentialism as such or argue that the theory of natural rights is ultimately correct. My objective in this work has been to conceptually clarify the notion of benefit-sharing and to inquire about the possible ways of justifying it, making use of some of the best-known arguments that are available in moral and political philosophy. Despite the fact that the inclusion of several approaches necessarily results in not doing full justice to the complexity and profundity of these theories, I believe that my work benefits from the adoption of an approach that draws on a variety of relevant sources in examining a specific issue.

This being a work of practical philosophy, I will most often rely on the arguments and concepts originating from political and moral philosophy[3]. Ted Schrecker has insisted that any *"responsible ethical analysis must not regard crucial background elements of the social and economic context /…/ as too big to change"* and has urged the linking of benefit-sharing discussion with the critique of "*market fundamentalism*"[4]. I agree that it is still worth asking regularly whether we have to take the current market-driven conditions of genetic research as a given and whether the purpose of practical philosophy is not to challenge the existing *status quo*, and stress the prescriptive instead of the descriptive. This means that the moral arguments about how things ought to be should not rely too heavily on the prescripted discourses so overwhelmingly employed by the very powers perpetuating the present situation. For example, the extension of the concept of property-rights (patenting) within all domains of biological resources is not something self-evident. However, perhaps unfortunately, my aim in this work is not too revolutionary. I will still be making heavy use of the traditional tools and theories of practical philosophy to provide for the possible ways of justifying a better outcome in this global genetic undertaking. And while aware of their shortcomings, I hope that these tools will not fail.

Additionally, my work will not focus on or solve the problem of human motivation or the *why care* question. I suppose in some ways the emphasis on concepts like rights and the consequentialist outcome-calculation, is "externalised ethics" as opposed to "internalised", in other words, one that starts

---

[3] I believe there is a large overlapping between the two but I also think there are issues that can reasonably be discussed as questions of moral philosophy or political philosophy.

[4] Ted Schrecker, "Benefit-Sharing in the New Genomic Marketplace: Expanding the Ethical Frame of Reference," in *Populations and Genetics: Legal and Socio-Ethical Perspectives*, ed. B.M.Knoppers (Leiden: Martinus Nijhoff, 2003), 406–407.

out from inward turned soul-seeking and probing of the self. Jürgen Habermas has stressed that *“moral insights effectively bind the will only when they are embedded in an ethical self-understanding that joins the concern about one’s own well-being with the interest in justice.”*[5] No amount of rights-talk can guarantee this inner motivation nor cure the evident “corruption of the will” but this does not mean that it cannot hope to influence or commence the process of individual thinking. Thus I will limit my focus to see whether a specific set of “tools of philosophy” can be successfully utilised in the interest of the problem under investigation. But I do not intend to argue that there are no other ways.

---

[5] Jürgen Habermas, “Are there Postmetaphysical Answers to the Question: What is the ‘Good Life?’” in *The Future of Human Nature* (Cambridge: Polity, 2003): 4.

CHAPTER 1. CONCEPTUAL ANALYSIS OF BENEFIT-SHARING[6]

The Human Genome Project and related activities in biomedicine and –technology have raised many important social, ethical, economic and political issues. One of the concepts being increasingly applied in all these areas is that of benefit-sharing — a usually rather vague insistence that benefits arising from genetic research and applications should be shared. In this chapter I propose to start with some descriptive material to introduce the subject. The documents I will focus on include the United Nations International Convention on Economic, Social and Cultural Rights, the United Nations Convention on Biological Diversity, the UNESCO Declaration on the Human Genome and the HUGO Statement on Benefit-Sharing. These documents themselves are not intended to serve as arguments but they are useful in explicating the rhetoric and the larger background for concerns that gave rise to benefit-sharing debate in the first place. I will then attempt to draw some conceptual conclusions from this material. I will also address concerns that question the appropriateness of benefit-sharing in human genetics.

1.1. Setting the stage

Although the publicity around benefit-sharing has recently been very much linked to the human genome research, benefit-sharing has been a significant issue for some time before the prominence of human genetics or even genetics. Perhaps the best known are the disputes concerning agricultural resources. There exist ample examples of cases where the results of research and development activities accomplished throughout the centuries by local communities are seized by big industry (as a rule originating from an industrialised country[7]), and the latter has the available resources to allow it to

---

[6] Some sections of this chapter are based on Kadri Simm, "Benefit-sharing: an inquiry regarding the meaning and limits of the concept in human genetic research," *Genomics, Society and Policy* 1, 2 (2005): 29–40; and Kadri Simm, "Benefit-Sharing and Population Biobanks," in *Ethics and Governance of Human Population Databases*, edited by V. Árnason et al. Cambridge: Cambridge University Press, 2006 (forthcoming).

[7] I will use terms developed and industrialised country interchangeably and in opposition to developing country. This is mostly based on the economic development of these countries but in biomedical research context I agree also with Ruth Macklin's suggestion that the major difference between those two groups lies in the likelihood of the majority of the population having access to the results of successful research. Ruth Macklin, *Double Standards in Medical Research in Developing Countries* (Cambridge: Cambridge University Press, 2004), 11.

"cross the finish line" and capitalise alone on a certain product through patenting.[8] Once the patent has been granted, the local community from a developing country has no means or resources to challenge the situation[9].

A good illustration of such activities in non-human genetics is the Indian Neem tree controversy. Neem tree has been used throughout centuries by local people for a variety of purposes, medicinal as well as other (thus the nick-name 'village pharmacy')[10]. Ground Neem was also used as a pesticide and research in India had been ongoing for decades to improve and stabilise the qualities of this product. Then a large chemical company Grace commenced similar research and succeeded in stabilising Neem-derived materials as pesticide. Grace proceeded to patent the product. The research done by Grace had made extensive use of the pre-existing knowledge that was the result of centuries of development activities by the locals. The pesticidal qualities of the tree were well-known. The patenting system however, rewarded solely Grace as the inventor and owner of specific knowledge. Grace's resources were incomparably larger and made it possible for them to invest extensively in this area. Being a large corporation they won the "race of patenting"[11]. Quite possibly the locals were not aware that there was such a race taking place as they were simply developing and improving something that was in common knowledge.

This example demonstrates how the patenting system privileges the contribution of a very few and essentially limits the negotiating space to one discourse. The management of biological resources especially in traditional cultures does not acknowledge the logic of patenting and denies that what is essentially a result of close cooperation can be "owned" by someone to the exclusion of others[12]. Of course, it is important to recognise also the often very substantial investments of the companies (after all, only a small section of the research yields the success-stories and high profit-figures). Nevertheless, within patenting discourse the extensive financial sums and the research capabilities of large enterprises dwarf the long-spanning and piecemeal contributions of local people. Benefit-sharing is an attempt to acknowledge the latter and provide a more inclusive and nuanced perspective for the assessment of these

---

[8] David Magnus, "International Agricultural Perspectives on Benefit-Sharing"; available from http://www.bioethics.upenn.edu/prog/benefit/pdf/Magnus_David.pdf; accessed 1.03.2005.

[9] It is important hereby to at least acknowledge the fact that "community" is a very complex, ambiguous and often contested notion. See for example HUGO Ethics Committee *Statement on Benefit-Sharing*, 2000; available from http://www.gene.ucl.ac.uk/hugo/benefit.html; accessed 14.03.2005.

[10] This example is described by David Magnus, "International Agricultural Perspectives".

[11] Although their patent was later invalidated by the European Union.

[12] Stephen B. Brush, "Bioprospecting the Public Domain," *Cultural Anthropology* 19, 4 (1999): 535–556.

contributions. In the criticisms of patenting, the arguments are not necessarily against the practice in principle, as it is acknowledged that investment and innovation should be rewarded. Rather concerns have been raised regarding the way patenting is conducted — through privileging certain powerful agents and by installing confrontation among those whose work and cooperation has been relevant for the final outcome. Besides ethical and economic aspects, concerns have also been voiced from scientific circles. It is claimed that patenting DNA sequences hinders research by rewarding those who do the fairly easy and routine work of sequencing and penalises those who are trying to research a more complex biological functions[13]. Additionally, patenting and the competitive and secretive commercial atmosphere surrounding for-profit research threatens the traditional openness and cooperation characterising academic research.

An appropriate example from human genetics is the Canavan-disease controversy[14]. Canavan disease is a neurological disorder of genetic origin that usually is lethal during the first decade of life. Group of researchers in the US in close partnership with the small community of the families of the affected children were collaborating to identify the genetic markers for the disease and ultimately to develop a screening test. The test would allow the families at risk to find out the likelihood of having an offspring with the disorder but it was also to be used in identifying an affected pregnancy or a patient herself. The Canavan gene was located in 1993 and a few years later the institution where the research was undertaken, was granted a patent. The patient holder — Miami Children's Hospital — insisted on royalties and also on control over other aspects of access. The parents who had participated in research sued the patent holder for restricting access to the test and limiting the number of tests a licensee can perform. Their main concern was not being left out of the sharing of profits but rather dismay at the perspective where those potentially affected by the disorder would not be able to take advantage of the test. Since then disease-advocacy groups have been careful to sign prior agreements regarding patenting and other benefit-sharing schemes.

But benefit-sharing is a much used framework also in clinical trials where intellectual property rights are not such a central issue. In human genetic research the trials taking place in developing country might result in products that will be unavailable to a large proportion of the local population. This can be

---

[13] Human Genome Organisation (HUGO), *Statement on the Patenting of DNA Sequences*, 1995; available from http://www.gene.ucl.ac.uk/hugo/patent; accessed 23.08.2005.

[14] This is a much-discussed example in the literature. Tom Reynolds, "Gene Patent Race Speeds Ahead Amid Controversy, Concern," *Journal of the National Cancer Institute* 92, 3 (2000): 184–186. Also a source on the Internet: American Medical Association homepage available from http://www.ama-assn.org/ama/pub/category/13570.html; accessed 23.08.2005.

because of the high cost or because results are not applicable or suitable for other reasons (e.g. when vaccines or drugs need vigilant storing conditions that are not available on necessary scale in the developing country). Also, overwhelmingly biomedical research focuses on the diseases of the affluent industrialised nations and disproportionately little research is done on illnesses that are prevalent among the populations of the developing countries. In a US National Bioethics Advisory Commission (NBAC) conducted survey 33% of US researchers and 48% of researchers abroad were of the opinion that the results of their research taking place in developing countries will not be available to this population in foreseeable future[15]. To ensure that populations participating in research and clinical trials are not solely carrying the burdens of trials, several guidelines stress that research should be responsive to the health care needs of the population. For example the World Medical Association Helsinki Declaration § 19 states: "*Medical research is only justified if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research*"[16]. Council for International Organisations of Medical Sciences (CIOMS) has similarly stressed in the International Ethical Guidelines for Biomedical Research Involving Human Subjects, Guideline 10:

> "*Before undertaking research in a population or community with limited resources, the sponsor and the investigator must make every effort to ensure that: (1) the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out; and (2) any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community*"[17].

This means that drug trials for diseases prevalent in the industrialised nations should not be carried out in developing countries[18]. Additionally, the

---

[15] The United States National Bioethics Advisory Commission (NBAC), *Ethical and Policy issues in International Research: Clinical Trials in Developing Countries,* 2001; available from http://bioethicsprint.bioethics.gov/reports/past_commissions/nbac_international.pdf; accessed 26.08.2005.

[16] World Medical Association (WMA), *Helsinki Declaration,* 2002; available from http://www.wma.net/e/policy/b3.htm; accessed 23.08.2005.

[17] Council for International Organisations of Medical Sciences (CIOMS), *International Ethical Guidelines for Biomedical Research Involving Human Subjects,* 2002; available from http://www.cioms.ch/guidelines_nov_2002_blurb.htm; accessed 23.08.2005. Guideline 10.

[18] An interesting discussion point is whether the same rule is valid when the roles are reversed — e.g. when trials for diseases rampant in developing countries are undertaken in developed countries. It could be suggested that since the subjects of industrialised countries are less vulnerable in terms having a choice for treatment also outside the

responsibility of researchers before the trial participants extends beyond the research project itself.

The examples above illustrate practices where the goods are extracted or services rendered from poorer countries and results labelled as private property. Often very little or nothing goes back to the communities that have originally contributed, for example by developing and nourishing certain plants through traditional agricultural techniques. In human genetics, the participants of even successful research might have limited or no access to the results of the project once trials are completed. Therefore one of the most influential arguments behind benefit-sharing refers to exploitation, to the past and present inequalities of power and resources in the world. These inequalities are capitalised upon by big international corporations, creating and enforcing further injustice between developing and developed countries. Both in terms of genetic and non-genetic resources relevant international regulations refer to a shared universal feeling of unfairness that arises when richer countries exploit the poorer ones[19]. Benefit-sharing is hence an attempt to change or at least alleviate this situation by insisting on the moral duty to share the benefits with all of the actors who have been part of the process of developing a certain good.

1.2. Rhetoric of benefit-sharing

Concerns for benefit-sharing have been reflected in a number of international statements. The United Nations International Convention on Economic, Social and Cultural Rights strove to broaden and elaborate the principles laid down in the UN Declaration of Human Rights some decades earlier[20]. The Convention article 15,1b expresses the following: *"The States Parties to the present Covenant recognise the right of everyone to enjoy the benefits of scientific progress and its applications"*. Obviously, "benefits of scientific progress" is a rather indefinite expression but the thrust of the potential right seems to refer to the benefits in the most all-encompassing and all-inclusive sense. Everyone thus appears to have a right to (enjoy) benefits that may eventually result from scientific activities.

---

clinical trial, this relationship should not necessarily be conceptualised in terms of exploitation but can be, for instance, characterised by altruism. This however needs further research, especially data on the social background of research participants in industrialised countries.

[19] Kåre Berg, "The Ethics of Benefit-Sharing," *Clinical Genetics* 59 (2001): 240–243.

[20] United Nations International Covenant on Economic, Social and Cultural Rights adopted and opened for signature, ratification and accession by General Assembly in December 1966, entered into force January 1976. Available from http://www.unhchr.ch/html/menu3/b/a_cescr.htm; accessed 14.03.2005.

On the other hand, the very next line in the Convention (15,1c) states that the parties also recognise the right of everyone: *"to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author."* This section relates to an important aspect of any discussion on benefit-sharing, namely that of intellectual property rights (IPR). IPR are rights given to people or organisations over the creations of their minds[21]. IPR are usually commercial monopolies, in case of patents limited to typically 20 years. IPR are at the heart of benefit-sharing debates because they effectively limit access to the results of research, and therefore carry a rationale of opposite direction to that of benefit-sharing that focuses on providing access.

How do these two neighbouring articles fit together? Or more bluntly, what if the abovementioned article 15, 1 c is incompatible with 15, 1 b? Can everyone have a right to enjoy the benefits of scientific progress and its applications while the authorship of these benefits is respected? How successfully can the ideals of benefiting everyone and the rules of authorship, for example in the form of intellectual property rights, coexist? Clearly some clarification is needed, both in understanding what the "right to benefits" exactly means and also, what is implied by the term "author". In these consecutive articles the Convention includes two very important principles but it does not offer solutions to the potential conflict between the values and ideals embraced by those principles.

Another international document stressing the importance of benefit-sharing is the United Nations Convention on Biological Diversity (excluding human genetic resources)[22]. The treaty has three main objectives: the conservation of biological diversity, the sustainable use of its components, and the fair and equitable sharing of the benefits from the use of genetic resources. Article 17,7 of Convention states: *"Each Contracting Party shall take legislative, administrative or policy measures /…/ with the aim of sharing in a fair and equitable way the results of research and development and the benefits arising from the commercial and other utilisation of genetic resources /…/"*. The Convention on Biological Diversity (CBD) has probably been most successful in implementing and promoting a common framework to ensure the actual bringing about of benefit-sharing practices. Guidelines have been implemented to operationalise the principles laid down in the Convention. These so-called "Bonn guidelines" have already made important contributions, particularly in establishing the international regime for accessing genetic resources and

---

[21] World Trade Organisation (WTO), *What are Intellectual Property Rights?* available from http://www.wto.org/english/tratop_e/trips_e/intel1_e.htm; accessed 23.08.2005.

[22] United Nations, *Convention on Biological Diversity* (CBD), 1992; available from http://www.biodiv.org/convention/articles.asp; accessed 14.03.2005.

benefit-sharing[23]. Nevertheless, the Convention text also stresses that in case of conflict with rights or obligations originating from other existing international agreements, the present treaty only has negotiating power if damage or threat to biological diversity is foreseen. In other words, in cases of controversy the ideals of equitable sharing should give way to competing concerns and principles laid down in other documents.

The CBD treaty acknowledges national sovereignty in all genetic resources ("*protection and guarantee of right of countries of origin of genetic resources*"[24]) and that informed consent or mutual agreements as regards to benefit-sharing should be in place before access to those resources is given[25]. In comparison with the previous document, the stress has moved from the"*rights of everyone*" to"*the sovereign rights of States*". The question pertinent from the point of view of the present work is whether this change in rhetoric would also entail a different justification for benefit-sharing or at least a change in responsibilities? The rights of States are in a different category altogether than those of everyone, or human rights, that were discussed in the UN International Convention on Economic, Social and Cultural Rights.

How is the need for benefit-sharing explained in the CBD? Firstly the intrinsic as well as instrumental value of biological diversity is recognised. The preamble mentions the desirability of sharing resources equitably and that certain human activities are presently threatening the biological diversity that local communities depend on. Access and sharing of genetic resources and new technologies is also vital to meet the food, health and other needs of the world

---

[23] Secretariat of the Convention on Biological Diversity, *Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilisation*, 2002; available from http://www.biodiv.org/doc/publications/cbd-bonn-gdls-en.pdf; accessed 28.08.2005.

[24] From the recommendations adopted by the Ad-Hoc Open-Ended Working Group on Access and Benefit-Sharing, Conference of the Parties to the Convention on Biological Diversity, 2004; available from http://www.biodiv.org/doc/meetings/cop/cop-07/official/cop-07-06-en.pdf; accessed 14.03.2005.

[25] Examples introduced on the convention's web-page include the following: (1)In 1995, the Philippines required bioprospectors to get "prior informed consent" from both the government and local peoples. (2)Costa Rica's National Institute of Biodiversity (INBIO) signed a historic bioprospecting agreement with a major drug company to receive funds and share in benefits from biological materials that are commercialised. (3) Countries of the Andean Pact (Colombia, Ecuador, Peru, Bolivia and Venezuela) have adopted laws and measures to regulate access to their genetic resources. The bio-prospector is required to meet certain conditions, such as the submission of duplicate samples of genetic resources collected to a designated institution; including a national institution in the collection of genetic resources; sharing existing information; sharing research results with the competent national authority; assisting in the strengthening of institutional capacities; and sharing specific financial or related benefits. Available from http://www.biodiv.org/doc/publications/guide.asp?id=action-int; accessed 15.08.2005.

population. It is also hoped that the conservation and sustainable use of biological diversity will strengthen friendly relations among states and contribute to the peace for humankind.

Another, perhaps more unofficial explanation refers to the fact that as the majority of the world's biological diversity is found in developing countries, benefit-sharing is a necessary instrument in guaranteeing their continuing interest in safeguarding this heritage. Resource-rich developing countries have already proven to be a necessary source for numerous medical breakthroughs and this abundance continues to play a vital role in the functioning and continuing expansion of the global pharmaceutical industry. This is echoed in a rather straightforward opinion of an official of the UN Environmental Programme (UNEP), reported as follows: "they [developing countries] would only be motivated to conserve their genetic resources if they could enjoy their benefits"[26]. Benefit-sharing here could be interpreted as more instrumental tool: it is a method to guarantee the cooperation of developing countries in research activities.

Thus benefit-sharing has received considerable attention in various international documents. But as this brief overview demonstrated, the topic is by no means exhausted by these declarations and treaties. The pronouncements of certain ideals often raise more questions than they offer answers to. While below I will focus more explicitly on the underlying reasoning and justification for benefit-sharing within human genetics, this historical excursion into the benefit-sharing rhetoric in non-human genetics and biological resources is important for several reasons. The mostly agricultural background to benefit-sharing can possibly explain some tendencies that have characterised this discussion within human genetics. Namely, the presupposition that in human genetic research (in parallel with agriculture, and say, mining) there exist certain clear-cut and tangible benefits and/or resources that can be easily assessed, accessed and distributed[27]. The fact that benefit-sharing discussion in non-human genetics has very much been based on the compensatory justice relying on the property argument, creates questionable parallels in the human genetics where the property arguments do not fit so easily.

The metaphor of extracting biological resources and turning these into benefits is less problematic in non-human genetics. The assumption that benefits are out there, almost graspable, disregards the social context of human genetics and the controversial nature, as well as the mere potentiality of many benefits. Because of the amount of hype that has surrounded human genetics (in comparison to plant and animal genetics), many overoptimistic visions as well as nightmares have become regarded as rather realistic benefits and burdens. In human genetics the principle of benefit-sharing is more complex as benefits are

---

[26] Words of Mr. Nehemiah Rotich (representative of the UN Environmental Programme) as reported in the report of the Ad-Hoc Open-Ended Working Group on Access and Benefit-Sharing.

[27] Thanks to Sue Weldon for discussing this with me.

controversial and the inclusion of medical sphere also means that the potential burdens might have different weight compared to non-human genetics. The fact that benefit-sharing has been a prominent discourse in biodiversity projects is important to bear in mind when analysing the application of this framework in human genetics.

My next example concerns human genetic resources — UNESCO Declaration on the Human Genome and Human Rights[28], article 12a states: "*Benefits from advances in biology, genetics and medicine, concerning the human genome, shall be made available to all, with due regard for the dignity and human rights of each individual*". Article 19a,iii follows:

> "*In the framework of international co-operation with developing countries, States should seek to encourage measures enabling: countries to benefit from the achievements of scientific and technological research so that their use in favour of economic and social progress can be to the benefit of all*".

Here the concepts of human rights and human dignity take central stage but in keeping with the character of such grand international pronouncements, certain vagueness remains. Exactly what kind of regard is necessitated by the existing human rights and dignity? In political philosophy, much has been written about the various claims, powers and liberties attached to the concept of rights. I will be scrutinising the relevance of rights discourse in benefit-sharing in chapter 4. But in terms of the UNESCO abovementioned declaration it is safe to suggest that human rights are here to be understood as those outlined in the Universal Declaration of Human Rights, a document inclusive of both negative and positive rights.

The clearest identification of the specific issue under investigation in the present work can be found in the Human Genome Organisation (HUGO) Ethics Committee statement devoted specifically to the subject matter of benefit-sharing (dated April 9th, 2000)[29]. HUGO is an international organisation established in 1989 uniting scientists and researchers of human genetics from around the globe. Besides scientific objectives, HUGO's mission statement also includes the aim of sponsoring the dialogue on ethical, social and legal aspects of genetic research and ensuring the *"regionally-appropriate, ethical utilisation of this information for the good of the individual and the society"*[30].

---

[28] United Nations Educational, Scientific and Cultural Organization (UNESCO) Declaration on the Human Genome and Human Rights, 1997; available from http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html; accessed 15.08.2005

[29] HUGO Ethics Committee, *Statement on Benefit-Sharing.*

[30] HUGO mission statement available from http://www.gene.ucl.ac.uk/hugo/mission.htm; accessed 14.03.2005.

The HUGO Ethics Committee has been outspoken on many weighty and debated issues around genetic research and their Statement on Benefit-Sharing was strongly echoed in the world of human genetics[31]. The statement focuses mainly on the question of distributing profits (also in non-monetary sense) that might arise from human genetic research through the participation of various communities. In contrast to the more general claims made in the abovementioned documents, the HUGO statement is exemplary because it attempts to provide a more principled and clearer justificatory basis for the concept of benefit-sharing. The following rationales are offered:

1) A descriptive argument — "*There is an emerging international consensus that benefits should be shared with participants*".
2) An argument from common heritage — we all share the same genome, there is a shared interest in genetic heritage of mankind, and the Human Genome Project should benefit all humanity.
3) Justice-based argument — compensatory (compensation in return for contribution), procedural (procedural justice should be adhered to in benefit-sharing) and distributive (equitable allocation and access to resources and goods) justice as important to consider.
4) Argument on solidarity on two levels. Firstly among specific group of participants, secondly in order to foster health for all humanity — benefits should not be limited strictly to those participating.

In my work I will make use of most of these arguments and attempt to categorise and analyse their potential in benefit-sharing debate. Below I have limited my attention to benefit-sharing in the medical sphere and more precisely in human genetic research. My aim is to draw a conceptual distinction between benefit-sharing in traditional medical context and benefit-sharing as a justice tool in global context.

1.3. Benefit-sharing in medical context

Historically, rewards or incentives for research participation in medical research were outlawed in order to ensure that no coercion or pressure was put on the volunteers. Much of the benefit-sharing discussion, with the few exceptions, has so far mostly been silent on this aspect, although it is clear that the promised

---

[31] See for example HUGO Ethics Committee, "Genetic Benefit-Sharing," *Science* 290,5489 (2000): 49; Bartha M. Knoppers, Ruth Chadwick, Hiraku Takebe et al., "HUGO urges genetic benefit-sharing", *Community Genetics* 3,2 (2000): 88–92; C. Weijer, "Benefit-sharing and other protections for communities in genetic research," *Clinical Genetics* 58 (2000): 367–368.

benefits might have direct relevance to the participation decision[32]. The statement by the UNEP official above alludes to the possibility that the benefits on offer may be the strongest factor influencing decisions about consent, whether these decisions are made communally or individually, and perhaps to the detriment of other concerns.

Benefit-sharing in the form of compensation for risks taken, time and effort spent, has been for a long time relevant in clinical trials. The risks posed to participants in clinical trials can be serious and direct, as new medical interventions are tried out and evaluated. Genetic research currently includes mostly giving of various samples and risks have so far been more theoretical — for example discrimination based on one's genetic makeup, concerns of privacy and of psychological stress when genetic tests reveal a potential disease without the possibility for cure. Benefit-sharing in this instance would be a compensatory activity geared towards those who have taken risks and accepted possible inconveniences that are necessary for research to take place and to possibly succeed. Without the willingness of volunteers, research would be impossible; their participation is a necessary component of any research, be it successful or not. Benefit-sharing as compensation recognises this important and essential partnership.

But as pointed out in the HUGO Statement on Benefit-Sharing, other justifications besides compensatory logic can ground this principle. An influential UK bioethics body, the Nuffield Council on Bioethics has published a report "The ethics of research related to health care in developing countries"[33]. The document outlines many issues that the Council argues should regulate the relationship between researchers and patients/communities. More specific examples of moral duties that can be relevant as regards benefit-sharing are:

- *Duty not to exploit to vulnerable.* This refers to the duty to abstain from taking advantage of the unequal circumstances of power, resources and opportunities in this world, a negative duty to refrain.
- *Duty to alleviate suffering.* Points to the necessity of providing benefits to those in need, a sort of positive requirement for those who have the power to act in alleviating suffering, based on concepts of solidarity and justice[34].

---

[32] Exceptions being here for instance HUGO *Statement on Benefit-Sharing*, and NBAC *Ethical and Policy issues in International Research: Clinical Trials in Developing Countries*.

[33] Nuffield Council on Bioethics, *The Ethics of Research Related to Health Care in Developing Countries*, 2002; available from http://www.nuffieldbioethics.org/publications/pp_0000000013.asp; accessed 25.08.2005.

[34] See Ruth Chadwick and Kåre Berg, "Solidarity and equity: new ethical frameworks for genetic databases," *Nature Review Genetics 2(*2001): 318–321; also the Nuffield Council on Bioethics, *The Ethics of Research Related to Health Care in Developing Countries*.

While compensatory justice is an appropriate rationale for sharing benefits among a clearly identifiable group of participants, then the duties outlined above are in principle significant also in a wider context. These moral obligations can be, and as I will argue below, already have been employed to provide a basis for benefit-sharing on a more inclusive and expanded level.

Benefit-sharing as an important component of research activity is undergoing changes because research itself has been transformed. I suggest that until relatively recently benefit-sharing in the sphere of medicine had been a rather local instrument, based primarily on the compensatory logic. Although pharmaceutical companies have been global organisations already for decades, research projects had still been limited to and largely characterised by a close relationship between research agency and the local community or individual patients. This bounded nature of the research setting and the more or less identifiable body of relevant actors and participants meant that benefit-sharing was a relatively specific, finite event. It was possible to ascertain those taking part and assess their claims within the medical, compensatory framework of benefit-sharing.

The Human Genome Project however, is an enterprise of much larger scale. One direction of genetic research has been the building up of large, sometimes population-based genetic databases. These can be defined as follows:

> "*genomic database is a collection of data arranged in a systematic way so as to be searchable./…/ The work associated with a database includes collecting, annotating, curating, storing, validating and preparing specific sets for transmission*"[35].

In some cases setting up databases has not meant the initiation of new collections but rather the reconfiguration and re-utilisation of already existing assemblages of human tissue samples as a genetic resource (e.g. the Umeå database in Sweden). Besides genetic information, databases are commonly associated with the inclusion of genealogical data and lifestyle information.

I would argue that the very characteristics of genetic information are a relevant aspect to consider when debating benefit-sharing in human genetics. This pertains to the fact that genetic information is shared and not individual-centred, and secondly, that it has important predictive qualities. The knowledge hidden within a person's genome has a definite relation to the genetic information of her relatives, a part of oneself simultaneously constitutes a part of the other. If one learns about her genetic risks, may or even should she disclose this semi-personal data to those concerned? What if the latter are vehemently against such knowledge? Ultimately who is the owner of such private information that bears relevance to more than one person or can it even be owned by any one person?

---

[35] HUGO, *Statement on Human Genomic Databases*, 2002; available from http://www.gene.ucl.ac.uk/hugo/HEC_Dec02.html; accessed 23.08.2005.

The whole subject matter of privacy — defined mostly as holding a *”distinctly negative connotation that is exclusionary and asocial”*[36] — acquires a new set of meanings when one is to consider this binding characteristic of genetic information. Attempts have been made to solve these issues through the traditional dichotomies of body/mind, self/other and the like.[37] But do the concepts of an individual, of freedom and of choice even make sense within this new condition? The medical and legal framework that has shaped the principles of handling medical information and guarding the doctor-patient relationship is focused on the person as a separate identity *“whose interests — and records — can neatly be separated from those of their families”*.[38] Genetic information through its relational character effectively contests such individual-centered perception of the world. It can of course be argued that the individual-centred discourse in principle has not been able to successfully address the fact of human interdependence — a worry shared by much of feminist and communitarian writing. This way genetics has accentuated an earlier concern and is not a manifestation of a wholly new phenomenon. For instance, women in their reproductive roles have always transgressed the boundaries of “separate individuals” as differentiation between persons in the traditional sense is impossible in pregnancies. Either way, genetics link people up with other people providing “overlapping medical destinies”[39]and a part of me will always constitute a part of my parents, siblings and offspring.

The second distinguishing characteristic of genetic information concerns its predictive nature. For instance, genetic tests can provide information on the likelihood of developing a certain disease. This might create psychological problems in cases where cure for the condition is not available but predictive tests are provided (e.g. Huntington’s chorea). Also, most tests only indicate the likelihood for developing a disease, in reality this might never happen. Another major concern in bioethics has been the impact of predictive testing on people’s work opportunities. Once the employers or insurers discover that a person is susceptible to fall ill, her chances of getting an insurance policy or even finding a suitable job, might be at stake[40]. It has been argued that genetic information is

---

[36] Rosalind Pollack Petchesky, *Abortion and Woman’s Choice. The State, Sexuality and Reproductive Freedom* (London: Verso, 1986): 3–4.

[37] Margrit Shildrick, *Leaky Bodies and Boundaries. Feminism, Postmodernism and (Bio)ethics* (London: Routledge, 1997), 181.

[38] Cathleen M. Kaveny, “Jurisprudence and Genetics,” *Theological Studies* 60, 1 (1999): 135.

[39] Ibid.

[40] A possible way of avoiding this situation is to outlaw discrimination based on genetic information. This principle has been articulated in several international documents (e.g. UNESCO Declaration on the Human Genome and Human Rights). Estonian Human Genes Research Act is an example of an appropriate national legislation. Available from http://www.geenivaramu.ee/index.php?lang=eng&sub=18&eetika=1; accessed 29.08.2005.

in principle no different from other medical information that can have the same predictive and transgenerational qualities[41]. While this may in principle be so on a theoretical level, I suggest that the very scope (e.g. large databases), as well as the hype around human genetic research aggravates these concerns in comparison with traditional medical information.

Human genetic databases have already positioned many new challenges for the frameworks of traditional medical ethics that have regulated the relationship between the patient and the researcher. One of the most discussed concepts possibly in need of redefinition in this light is that of informed consent[42]. Informed consent traditionally involves the voluntary agreement to participate in a specific research project, and the requirement to inform the participant of all the possible harms and benefits that may arise from participation. This mechanism of protecting the subjects of medical research against involuntary acts was established after the Nuremberg trials, where the atrocities of the Nazi medical research were uncovered. But the large genetic databases problematise the possibility of a fixed and specific research objective that the participants can consent to because the rationale of the database lies exactly in the potential to use this source continuously for new, needed research.

Genetic research as undertaken in the form of genetic databases swells the number of participants considerably and also blurs the very concept of participant as genetic information is by nature shared. Those possibly affected by the research can be a much larger group of people than those participating in the traditional sense of the word. Large genetic databases also aggravate the issue of benefit-sharing as unexpected benefits and harms may arise when new research is undertaken. The question of sharing with whom is also unclear. In case of large population based genetic databases the question will inevitably be raised as to who specifically will benefit? Can and should we define a relevant recipient community as not everyone will be involved? Reasoning behind benefit-sharing logically delineates the recipient community. For example one can start with abstract justification that will determine the circle of those to whom it applies; or *vice versa*, when one is concerned with certain individuals, communities, peoples etc., it is possible therefore to argue for a benefit-sharing principle that would take specifically their interests into account.

Arguments for the application of the concept of solidarity have been made[43], so that benefits arising from research would not be shared based on the principles of medical ethics, stressing for example, compensation for risks

---

[41] Søren Holm, "There is nothing special about genetic information," in *Genetic Information, Acquisition, Access, and Control*, eds. A. K. Thompson, R. Chadwick (New York: Kluwer Academic/Plenum Publishers, 1999): 97–103.

[42] A useful synthesis of the various approaches is provided in Ants Nõmper, “Open Consent — A New Form of Informed Consent for Population Genetic Databases” (Ph.D.diss., University of Tartu, 2005).

[43] HUGO, *Statement on Benefit-Sharing*.

taken, but based on principles of social justice. It is this line of thought linking benefit-sharing to issues of justice and the disconnection of the issue from the particularities of medical sphere (in terms of justifications and general principles) that adds a new angle to the benefit-sharing discussion. Concerns of international justice are increasingly juxtaposed to the issues of medical ethics. An example of this concerns the recent introduction of the requirement of universal benefit-sharing of the fruits of genetic research.

1.4. Benefit-sharing in global context

Discussions regarding benefit-sharing in human genetic research have increasingly stressed that everyone should benefit and that the entire humankind should be involved in the sharing[44]. Here the concept is employed to fight the activities of patenting and commercialisation that monopolise and limit access to the results of genetic research. Besides solidarity the right to benefit from genetic research could then be based on a fact that humans share 99% of the genome. To quote Ortúzar: *"there is no reason to confer benefit exclusively on the population which is the subject of the research /…/ all benefit derived from genetic research on populations should be available to anyone in need of the health improvement offered by it."*[45]

UNAIDS guideline on the ethical considerations in HIV/AIDS preventive vaccines research states that any vaccine found effective *"should be made available as soon as possible…to other populations at high risk of HIV infection"*[46]. Indeed, benefits to participants can be seen as unfair from the point of view of universal benefit-sharing. Instead of a risk-centred justification of benefit-sharing in medical context, arguments from solidarity and justice are voiced as the rationale for this framework.

A popular argument invokes globalisation as a phenomenon that has introduced compelling reasons for some redistributive action. Globalisation has been defined as "*a corporate-driven process of investment, trade, and*

---

[44] See for example Levi Mansur, "Gene Discovery, Ownership and Access for Developing Countries in the Era of Molecular Genetics," *Electronic Journal of Biotechnology* 5, 1 (2002); available from http://www.ejbiotechnology.info/content/vol5/issue1/issues/05/); accessed 12.12.2004; María Graciela de Ortúzar, "Towards a Universal Definition of 'Benefit-Sharing," in *Populations and Genetics: Legal and Socio-Ethical Perspectives,* ed. B. M. Knoppers (Leiden: Martinus Nijhoff, 2003): 473–486; Schrecker, "Benefit-Sharing in the New Genomic Marketplace," 405–422.

[45] Ortúzar, "Towards a Universal Definition," 478.

[46] Joint United Nations Programme on HIV/AIDS (UNAIDS), *Ethical considerations in HIV/AIDS preventive vaccines research*, 2004; available from http://www.unaids.org/html/pub/publications/irc-pub01/jc072-ethicalcons_en_pdf.pdf; accessed 15.08.2005 : 13.

technological change in an expanding market, with continuously expanding mass communications, and homogenisation and standardisation of production and consumption"[47]. The aim is to eliminate barriers so that goods, services, people, investments, ideas and information might flow across borders. Globalisation is a buzz-word that is linked to numerous economic, legal, social, cultural and other concerns. While often conceptualised as a wholly problematic phenomenon, globalisation can also be seen in positive ways: in influencing self-awareness of people and societies, in leading a transformation in the consciousness of the world and pushing towards self-reflexivity as our complex interdependence becomes apparent[48].

The concerns that globalisation has brought to the fore have been linked to a growing disillusionment that the rules of formal equality between states as well as individuals have produced so little distributional equality. The mere fact of existing inequalities is not a sufficient argument for action for most approaches in political philosophy (excluding the radical egalitarians for whom inequality in itself is immoral). Most political views would allow for the inequalities if these can be justified. However, it has been persuasively demonstrated that the present global economic and political order is still very much a continuation of the old inequalities and unjust practices[49]. Many of the perceived injustices are not particular to genetic research in any way but are a pervasive feature throughout the activities of global capitalism, whether it is the "regime shopping" for suitable tax or other legal conditions or "social dumping" for various social and environmental bargains[50].

Insisting that the human genome is a common property or that genetic databases should be global public goods[51] — all these different arguments have in common a worry that the present biotech revolution will turn out to increase the inequalities of the world and enlarge the so-called North-South divide[52].

---

[47] Asbjørn Eide, "Universalising Human Rights: the Process and Challenges in the Age of Globalisation," in *Debates on Issues of Our Common Future,* ed. W.Krull (Göttingen: Velbrück Wissenschaft, 2000): 38.

[48] Bryan S. Turner and Chris Rojek, *Society and Culture. Principles of Scarcity and Solidarity* (London: Sage Publications, 2001): 14.

[49] See for example Thomas Pogge, *World Poverty and Human Rights* (Cambridge: Polity Press, 2002); David Miller, "Justice and Global Inequality," *Inequality, Globalisation and World Politics*, ed. A.Hurrell, N.Woods (Oxford: Oxford University Press, 1999): 187–210.

[50] Bob Deacon, *Global Social Policy : International Organisations and the Future of Welfare* (London: Sage Publications, 1997): 11.

[51] HUGO Ethics Committee, *Statement on Human Genomic Databases*.

[52] World Health Organisation, *Genomics and World Health*, 2002; available from http://whqlibdoc.who.int/hq/2002/a74580.pdf; accessed 12.01.2005; Patricia A. King, "The Past as Prologue: Race, Class, and Gene Discrimination," in *Gene Mapping. Using Law and Ethics as Guides,* ed. George J. Annas, Sherman Elias (New York: Oxford University Press, 1992): 95.

Reversing the argument, it may also be suggested that genetics might have enormous potential in levelling the existing inequalities and providing for a more just and equitable existence. Few would dispute that the impact the application of genetics might have in specific societies as well as in global context, owes much to the way its fruits as well as its burdens will be distributed. Hence the rise of benefit-sharing concept as most would agree that the potential for both greater good and greater harm is there.

As regards genetic research, globalisation has raised a number of new issues. The potential of genetics to influence and transform spheres that were so far largely "up to nature" has been both hailed and condemned. If we leave aside the "playing God" arguments that denounce these developments in principle, we are often left with the concerns over the coupling of globalisation and corporate biotechnology. Commercialisation has meant that main investments in health care and genomics nowadays originate from the private sector and the slice of non-profit research is getting smaller. It is also increasingly difficult to draw a clear line between commercial biomedical research and other fields: technologies and knowledge merge across domains blurring the boundaries between medicine, food, agriculture, cosmetics and other sectors[53]. One of the reasons why benefit-sharing has increasingly been applied outside the confines of the medical sphere is that arguably medicine itself has changed considerably. Certainly not all medicine can be straightforwardly equated with business but the developments in genetics have brought this characteristic to the forefront, and gradually our hopes and dreams in medicine are linked up with the rather expensive, as well as extravagant promises of genetics. The medical industry has become big business, for example the pharmaceutical trade sector has for a while been the most profitable in the world[54]. The stringent ethical principles associated traditionally with medical research have required a whole new background.

Perhaps benefit-sharing has become such an issue because people have realised that their volunteering is not matched with altruism from the other side and consequently compensation to enforce a degree of justice is required? Hereby it is important to acknowledge that much of research is still sponsored by governmental or non-profit organisations that respond more directly to public health needs on various scale and are less (or even not at all) motivated by profit-figures that are an important consideration in for-profit enterprises. Consequently attention should be paid to the different capabilities of the former in providing benefits of the scale and scope that are sometimes associated with pharmaceutical industry. But if big profits are made by industry, then a feeling of fairness would demand the sharing of these profits with participants in some

---

[53] Robert L Ostergard Jr., Matthew Tubin, Jordan Altman, "Stealing from the Past: globalisation, strategic formation and the use of indigenous intellectual property in the biotechnology industry," *Third World Quarterly* 22, 4 (2001): 643–656.

[54] HUGO Ethics Committee, "Genetic Benefit-sharing", 49.

form or other. For example, pharmaceutical giant Eli Lily derived two cancer drugs from a Madagascar plant, the sales of which have exceeded $100 million[55]. Madagascar has seen none of that profit. An example from human genetics concerns an isolated cell line from the Hagahai people in Papua New Guinea that promises to be valuable in diagnosis of leukaemia and related diseases[56]. The commercialisation of research has meant that the contributions that were traditionally interpreted within the altruistic framework characterising scientific research are increasingly viewed as investments or calculated stakes in an arrangement geared to produce profit.

To conclude, I do not argue for the counterpositioning of medical sphere versus new genetics-as-business sphere in terms of benefit-sharing. I would rather insist that the increasing prevalence of market forces in biomedical research as well as other factors, like globalisation and developments in information and other technologies, are having a considerable effect on the rationale for benefit-sharing. Presently the industrialised countries are setting the research agenda and priorities as well as overwhelmingly reaping the benefits, raising concerns of distributive justice on global scale. Discourses are shifting and new arguments and justifications are advanced through the introduction of alternative perspectives and domains. However, to discuss these transformations further, the notion of benefit should be clarified.

1.5. Defining benefits

HUGO ethics committee has expressed in its Statement on Benefit-Sharing the following:

> *"A benefit is a good that contributes to the well-being of an individual and/or a given community (e.g. by region, tribe, disease-group...). Benefits transcend avoidance of harm (non-maleficence) in so far as they promote the welfare of an individual and/or of a community. Thus, a benefit is not identical with profit in the monetary or economic sense. Determining a benefit depends on needs, values, priorities and cultural expectations."*

Firstly, benefit is clearly a positive change for the recipient(s) and should not be defined as simply providing a neutral result with the insistence that potential burden was avoided (benefit here cannot be defined as the avoidance of a burden). Secondly, and more importantly, the definition recognises that benefits or goods cannot be regarded as identical with monetary gain and are not to be established as neutral or objective facts but are inherently value-laden.

---

[55] Ostergard et al., "Stealing from the Past", 651.

[56] Ibid., 652.

Benefits put forward by scientists, as well as the pharmaceutical industry, patients, investors and public health officials span a wide array of potential valued "goods", starting from improved health and better science to financial gains and to wider social benefits. What is behind the notions of benefits and burdens of genetic research that are utilised in various discussions? The HUGO definition is rather vague and I think intended to be such, but below I sketch an outline of issues that have been named by various actors internationally and especially in the context of genetic databases. This overview of the health, financial and scientific benefits is by no means exhaustive but rather illustrative and no judgment is presently exercised as to the actual deliverability of these promises.

	Health benefits	**Commercial benefits**	**Scientific benefits**
Individual level	Designer drugs and other individual aspects of "personalised medicine"	Profits to the investors	Non-instrumental knowledge: development of science and gaining of new information as a value in itself, regardless of the fact whether it is useful to humans
Communal level	Relief to disease-related populations etc	Non-medical benefits to communities; capability-building	
National, state level	Efficient health care services, policy planning etc	Development of biotech and related sectors, new jobs etc; capability-building	
Global level	Eradication of diseases etc		

This table demonstrates the wide-ranging scope of the hopes and dreams we have with respect to developments in genetic research. The table is also illustrative of the claim that insists on a distinction between two different aspects in the benefit-sharing framework. A differentiation needs to be made between the *universal* list above, describing the entire positive potential of the genetic enterprise, and a *specific* benefit-sharing framework directed towards those that directly participate in research. Universal benefit-sharing engages with the concerns of global justice on the widest possible sense, whereas specific benefit-sharing is a continuation and elaboration of a framework originating from medical ethics.

These two levels need to be kept separately if we still want to make use of the same sharing framework and by differentiating between universal and specific sharing much confusion is avoided because many benefit-sharing arguments function only in specific context, whereas others have relevance universally. For example compensation for risks taken is an important aspect where smaller research projects are concerned whereas fairness gains significance in cases of successful drug development for diseases rampant in the poorer areas of the world. Some of the uncertainties and doubts that have accompanied the benefit-sharing discussion in genetic research might have to do with the fact that the arguments based on international injustice might, for example, not fit so well into the research frameworks of the developed countries. For example, altruistic participation might still be a possibility in industrialised countries, whereas similar rationale is much more difficult to accept when research is undertaken in developing countries as the inequalities of power and the local deprived conditions limit the acceptability of this principle.

Of course, as discussed above, the intergenerational nature of genetic information does not allow for an easy delineation of those who are directly participating in research from those that it might still directly affect. Increasingly there is a consensus in human genetic research that to limit the sharing of benefits only to those who were directly involved is not justified and this already marks a shift from a strictly reciprocal model of distributive justice. Access to successful results of research in terms of community or population is an important factor in determining the justice of the research setup[57]. And universal benefit-sharing claims strive towards recognition that these various types of benefits should be available on the global level. Mostly the stress has been on health-related benefits but increasingly benefits can be defined in other terms — e.g. research cooperation, training of local researchers etc. Admittedly, in many cases the question is not in "handing out" benefits but rather in allowing access to various products and technologies. This access is severely restricted for many poor countries for various reasons. There is of course the issue of finances as access to drugs, therapies, technologies and know-how is restricted with patents or high costs. But it is also a larger problem of limited capabilities — in many instances knowledge, innovation and novel practices are simply unusable in the deprived conditions prevalent in many countries.

Is benefit-sharing still a concern when there are no scientific results after the research project has been completed? What becomes of benefit-sharing when there are no benefits, when research is unsuccessful? It has been argued that the very idea of benefit-sharing presupposes that there are benefits available[58]. But if benefit-sharing is interpreted on a wider, global level and as a process that is not so outcome-centred, this might not be so. Benefit is not identical with profit. Capability-building, for example through training local competencies, can be part of the research process and is in some sense independent from research results. Even if no products result, valuable information that can guide further

---

[57] Garrath Williams, Doris Schroeder, "Human genetic banking: altruism, benefit and consent,“ *New Genetics and Society* 23, 1(2004): 89–103.

[58] Berg, "The Ethics of Benefit-Sharing," 242.

research is most likely still achieved. This issue is closely linked to how benefits are defined — whether they are determined before the start of research and cannot be renegotiated; whether they are defined in terms of directly originating from research or can anything be defined as a benefit by participants or community (e.g. something essentially unrelated to the potential outcomes of research)? Ultimately, benefit-sharing might have strong procedural justice qualities in providing for a sense of inclusion and attention that would be of distinct relevance compared to that of distributive justice.

Benefit-sharing seems to be on the one hand fuelled by feelings of injustice emerging from the inequalities of power between the global medical and pharmaceutical industry and the resource-rich less developed countries; on the other hand the scene has been much influenced by the often over-hyped visions of grand future developments. Increasingly benefit-sharing is viewed not within compensatory or reciprocal framework but as an ethical requirement regardless of what or even whether benefits accrue or not. It is not a bargaining ground or a market exchange; desert is not a proper principle for benefit distribution. Instead, sharing could be based on need, equality or other distributive principles or moral rules (for example moral obligations of rich countries before the deprived ones). Benefit-sharing framework should include a number of principles and not be predefined by certain limited set of concerns that are to be applied universally[59]. In that case the fact that direct benefits do not result has in principle no relevance in benefit-sharing. It could be a moral obligation independent of actual research results.

1.6. Some concerns regarding the concept of universal benefit-sharing

Developments in genetics and biotechnology have raised widespread hopes to battle the diseases and therefore improve the quality of life of millions, and also, to make big profits on the side. However, I think that prominence of benefit-sharing discussions cannot be attributed solely to those worthy humanistic as well as popular pecuniary hopes. While the hype certainly has a role in the rise and intensity of the debate, benefit-sharing is strengthened through issues that are far removed from the particular research activities. I refer to a larger framework of structural world inequality in terms of opportunities and resources that stem from various sources, be it inherited from colonisation experiences or the current international establishment of market-oriented liberal capitalism that favours certain prominent players and regulations in the ordering of our world.

---

[59] Graeme Laurie, Kathryn G. Hunter, “Benefit-sharing and public trust in genetic research,“ in *Blood and Data. Ethical, Legal and Social Aspects of Human Genetic Databases,* ed. By G. Árnason, S. Nordal, V. Árnason (Reykjavik: University of Iceland Press and the Centre for Ethics, 2004): 327.

Essentially, it is not a genetic, business or medical issue but a political one. That is — the current dissatisfaction and injustice that forms the basis for a universal benefit-sharing requirement, is larger than only genetic research allows for. It is clear that benefit-sharing is hoped somewhat to address this dissatisfaction, despite the fact that much of it stems from areas not connected to genetic research. But can benefit-sharing framework respond adequately to those concerns that arise from this larger background of injustice issues? Genetics is not an only health issue and even health itself does not contain the various aspects of human existence that are relevant from the justice point of view. So what can be done to remedy the situation and guarantee a more favourable outcome?

To my mind the problem is that at least *prima facie*, a benefit-sharing framework is not able to respond adequately to those concerns that originate from this larger background of injustice issues. Benefits from genetic research, despite being potentially very widely applicable and relevant to human health, will in foreseeable future be able to address a limited cluster of health care issues[60]. The relevance of genetic research to the most burning global health care issues will likely be restricted due to several reasons. Firstly international health organisations as well as alliances among nation-states are still grappling with the disproportionate research investment into the diseases of the industrialised countries in comparison with the developing ones. Presently most of research is done on diseases prevalent in industrialised countries and the health care problems of the majority of the world population are paid much less scientific attention. This is the infamous 90/10 gap where 90% of the investments into medical research are spent on the health care issues of the 10% of the world population[61]. Of 1233 drugs approved for market between1975–1999 only 13 were designed specifically for tropical diseases (and six of these were sponsored by international organisations)[62]. Genetic research is increasingly market-driven and not need-driven[63]. Secondly, as a rule, new drugs and therapies are usually quite costly. While the prices decrease in time, the availability and pricing of drugs is very much influenced by large pharmaceutical companies that attempt to make as much profit as possible from all new products.

---

[60] For an optimistic but rather rare appraisal of biotechnologies capable of implementing significant change in the developing countries within the next 5–10 years see Abdallah S. Daar et al., “Top ten biotechnologies for improving health in developing countries,” *Nature Genetics* 32, (2002): 229–232.

[61] Global Forum for Health Research, *The 10/90 Report on Health Research,* 2000; available from http://www.globalforumhealth.org/Site/002__What%20we%20do/ 005__Publications/ 001__10%2090%20reports.php; accessed 28.08.2005.

[62] WHO, *Genomics and World Health*, 18.

[63] This of course opens up another huge debate, namely that of human needs. I will not pursue it here.

Applications from traditional (meaning non-genetic) medicine, improvements in hygiene and nutrition are still more useful in helping the populations of developing countries to achieve better health and quality of life. Currently, around 800 million people, or 18% of the world's population go hungry every day and suffer the related consequences to their health; 1,1 billion do not have access to safe water[64]. Thus even very generous redistributive actions resulting from genetic research or new medical research as such, will not have the effects in international situation that many are hoping for. It is the fair provision of the most basic medicines that would benefit the populations of developing countries the most. This of course links back to the question whether shared benefits would necessarily have to be related to or result from genetic research? It is possible that benefit-sharing within genetic research could allow for anything to be shared, as long as it is defined as a benefit by substantial amount of stakeholders. This, on the other hand, raises the problem I alluded to previously — namely that benefits distributed via genetic research (whether they themselves are genetic or not) are not in any way a sufficient measure to alleviate the problems where genetic research forms only a minor or even no part. If there is dissatisfaction with the current practices of conducting research in developing countries and the rules of patenting and intellectual property rights are seen as favouring certain interests (e.g. the interests of those who drafted them), then benefit-sharing activities at least as traditionally practiced within scientific research projects, are not adequate responses. If patenting system is unfair, then benefit-sharing concept as presently applied in human genetics is not able to challenge that unfairness sufficiently. Rather changes in policy are required.

Secondly, much of the discussion in benefit-sharing discourse is diffuse, ambiguous and incoherent, as it utilises several arguments that may exclude each other and thus it can be 'dealt with' through dispersing with a few coloured ribbons and glass-beads, so to speak. Justifications for benefit-sharing can be contradictory: argument from solidarity would produce a different benefit-sharing arrangement than that based on taking direct medical risks. The logic of intellectual property rights often does not recognise the contributions that were essential in developing a certain type of resource. Many would refer to a certain 'gut-feeling' that in principle benefits are due in return for a contribution but in the complexities of genetic research these are in many cases very hard to establish. Verbalising this feeling can result in quite different philosophical and political principles pertaining to distributive justice, solidarity, human dignity and others.

The exceptions here are the monogenetic diseases and disease-advocacy groups in US have in some cases been very successful in negotiating for direct benefits as their contributions are easy to prove[65]. On the other hand,

---

[64] United Nations Development Programme, *Human Development Report,* 2003;available from http://www.undp.org/hdr2003/; accessed 15.01.2005.

[65] Some of the best known examples are PXE International and Alpha-One Foundation.

monogenetic diseases are very rare, and most of the elated expectations from genetics actually hope for discoveries in the cure of common complex diseases. Research on these diseases, especially because they are strongly linked to environmental factors, will necessarily involve very many participants and samples. Involvement of hundreds and thousands would be needed even to start contemplating any relations between a disease occurrence, DNA and environmental factors. This also means that tracking someone's individual contribution would be unthinkable. The quality of the relationship — the interpretations that can be drawn — here really comes with quantity. Furthermore, in many instances research does not produce any benefits as science normally proceeds through a number of unsuccessful attempts.

Benefit-sharing within specific research projects in both non-human and human genetics is an increasingly recognised and exercised moral duty. The reasoning based on the compensation for risks taken or the acknowledgement of other types of contributions has been central in providing justification for such practices. But as argued, these grounds are insufficient for the purposes of a much larger framework that pleads for more universal solutions to problems that might be quite far removed from the specific research projects. The traditional medical framework of human genetics and compensation for risks cannot be highly relevant in universal benefit-sharing. Benefit-sharing as a framework originating from research is simply inadequate for enforcing the claims that are currently made within it to alleviate the widening gap between the developed and developing countries. The reasons behind currently existing injustice are manifold and complex and the rather specific line of benefit-sharing thought originating from the uneasy mixture of academic research and business activities does not look very promising. Turning to the wider issues of structural inequalities and injustice in the world, some other ways of arguing for change must be found.

If universal benefit-sharing claims are to succeed, the justifications for this framework need to rely on additional arguments. Much of my work is focused exactly on the analysis of those possible rationales where the focus has moved from responding to a specific research situation to responding to the much more complex subject matter of the human condition. This point is also echoed in an understanding that public health is very much influenced by socioeconomic factors: whether we live long has a lot to do with where we are born, how well-off are our parents and whether we have a good education and job. Health, individually and universally, is not only a medical issue. It is therefore justified that benefit-sharing is inclusive of those other factors that determine our health and is engaged with issues originating outside of medicine.

Benefit-sharing should be used to its maximum potential in the present form, including, if possible, the sharing of benefits to those not directly involved, but that will not be even a remotely adequate solution for the international social justice problems. Therefore benefit-sharing discussion needs to adopt a stronger and more precise vocabulary and include arguments from diverse perspectives of politics and economy.

1.7. Some words on responsibilities

An important question within benefit-sharing is that of responsibilities. Who should take care of these practices or be held accountable if benefits are not shared? This is a challenging subject matter that has a complex answer, or actually many answers. While this is not the focus of my work, in principle the issue is very much linked to how benefit-sharing is justified. This means that the responsibilities ensue from how benefit-sharing as a moral requirement is reasoned for in particular instances. Within specific research projects that are concerned with the sharing of benefits within a limited group of stakeholders, the responsibilities are easier to settle. The reciprocity characterising the clinical trials or some other research event points to the appropriate duties of researchers and sponsors[66]. Traditionally these responsibilities have included the rule of minimising risk for participants, obtaining informed voluntary consent and ensuring other aspects of the ethics of health care research. The risk discourse delineates a recipient community and those responsible for creating these risks have a duty to compensate within the reciprocal setting. Increasingly international and national guidelines have stressed the duty to provide post-trials benefits (usually in the form of medical care and drugs) to participants and the research projects would need to outline these schemes before the start of research[67].

In comparison with the medico-ethical regulations stressing mostly the responsibilities of sponsors and researchers, the Nuffield Council on Bioethics has added another subject. The Council has stressed that it is the responsibility of governments to provide their citizens with the needed health care products and services and such duties cannot reside with sponsors or researchers. The Council states: "*responsibility for making a vaccine, treatment or other intervention available will not lie solely with any one group. If a national government has agreed to allow a trial to take place, it presumably accepts*

---

[66] For example CIOMS, *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, guidelines 10 and 21.; NBAC, Ethical and Policy issues.

[67] WMA, *Helsinki Declaration*, principle 30; European Group on Ethics in Science and New Technologies, Ethical Aspects of Clinical Research in Developing Countries, 2003; available from http://www.europa.eu.int/comm/european_group_ethics/docs/avis17_en.pdf; accessed 26.08.2005; similar regulations have been accepted by various national bodies e.g. the Brazilian National Health Council, Resolution 196/96 — On Research Involving Human Subjects, 1996; available from http://www.aids.gov.br/resolution_196.htm; accessed 17.08.2005.

some responsibility to act on the results”[68]. My interpretation is that the Council is already at least implicitly referring to the requirement for a wider and more inclusive benefit-sharing that would stand outside the specific sharing agreements between participants and researchers (after all, the government has responsibilities before all citizens and not only those participating in research). The Council insists that providing citizens with health care products and services in general, cannot be an issue solved through the benefit-sharing schemes of specific research projects. The duties before participants and community therefore do not arise solely from reciprocal justice, but from distributive justice responsive to the needs of the community.

The way benefit-sharing is reasoned is indicative also of responsibility. For example, if benefit-sharing is a compensation for participation, then the responsibilities lie with those who have set up the collaboration but also with those who have provided the framework and regulations for these events. When universal benefit-sharing is based on the language of human rights — e.g. everyone has the right to benefit — then responsibilities lie with those who are obligated to fulfil and guard such rights. In terms of *universal* sharing, the “international community” (meaning international organisations) has been called upon to take redistribution into their hands[69]. It has been proposed that pharmaceutical companies sponsoring research take an active part in benefit-sharing: for example the HUGO ethics committee has suggested that companies should set aside 1–3% of annual net profit to support health care infrastructure and/or to humanitarian efforts[70]. Various partnerships and collaborative agreements between governments, research agencies, NGOs and others are a possibility to further these activities.

Although the sovereignty and formal equality of states has traditionally left the existing social and economic inequalities of peoples outside the scope of international law and global market regulations, this has started to change, as illustrated by the growing empowerment of the human rights discourse and the fact of international courts and organisations making demands on national governments. The hopes for some common global policies developing from within this framework should not be unfound. There is political anxiety that new instruments and policies are needed to remedy the existing ills that globalisation has made visible and exaggerated. This is a global governance solution, with the emphasis on the role of supranational and international organisations in enforcing social and economic goals. Generally it can be argued that laying sole responsibility for benefit-sharing on such scale on research agencies and sponsors is not justified, as the underlying concerns behind calls for benefit-sharing stem from a much wider background of discontent.

---

[68] Nuffield Council, *The Ethics of Research Related to Healthcare in Developing Countries,* 122.

[69] Ortúzar, “Towards a Universal Definition,” 481.

[70] HUGO, *Statement on Benefit-Sharing.*

1.8. Against benefit-sharing

Finally, before focusing further on the possible justifications of benefit-sharing, it should be mentioned that there remain also arguments that dispute the application of benefit-sharing framework in genetics as such. These are mostly related to an understanding that discussions of benefit-sharing actually legitimate the attempts to commercialise and profit from the (human) genome. These views could be based on an understanding that genetic research is part of the larger humane project of medicine where financial or other aspects should not compete with the overarching values like human health and quality of life. If human genetic research is about locating genes, understanding their functions and possibly attempting to modify these with the aim of treating or preventing the occurrence of a gene-related disease, it could be asked why are there such heated debates on benefit-sharing? After all, so far the understanding has been that the results of scientific inquiries suffice as the benefits that are then available to the public. Whatever has become of the concept of altruism in medical research? Why shouldn't we nowadays continue this honourable tradition of volunteering to help science to progress, so that future generations may have a life of less pain and illness? Indeed, some might feel offended when their honest altruistic participation is answered with the promise of a benefit. "This it not why I am doing it" — people would say.

Debates on benefit-sharing are sometimes viewed as a side-effect of commercialisation. In other words, benefit-sharing is perceived as in some ways contributing to this phenomenon by accepting the premise of trading or business-like exchange.

Ruth Chadwick and Adam Hedgecoe[71] have classified the arguments against commercialisation of the human genome into deontological and consequential camps. The latter position anticipates the results of commercialisation of the human genome to be unjust and tragic and therefore the process should be halted. Some of these negative consequences could for instance lie in the commercialisation of the university-based research and thus the compromising of the quality of the work done there. Commercial data sharing practices could halt scientific progress as new knowledge is rapidly patented and excluded from the common resources[72]. The pressure to offer genetic services on the market could affect the quality and evaluation of these novel measures[73]. Also,

---

[71] Ruth Chadwick and Adam Hedgecoe, "Commercialisation of the human genome," in *A Companion to Genethics*, eds. J. Burley, J. Harris (Oxford: Blackwell, 2004): 334–345.

[72] Jonathan King, "Gene Patents Retard the Protection of Human Health," *GeneWatch* 10, 2–3 (1996): 10–11.

[73] Timothy Caulfield, "Regulating the Commercialisation of Human Genetics. Can We Address the Big Concerns?" in *Genetic Information. Acquisition, Access, and Control*, eds. A. Thompson, R. Chadwick (New York: Kluwer Academic/Plenum Publishers, 1999): 149–162.

metaphysical threats to the “ethical self-understanding of the species” that would eventually lead to the abandonment of the moral commitment are highlighted as the potential outcomes of genetic engineering and the like[74].

The deontological arguments start from the premise that profiting from human genome is inherently immoral as the value of genome and genes cannot be represented in monetary terms[75]. Various understandings of humanist and religious accounts on human bodily integrity and sacredness underlie this standpoint[76]. Money dirties and belittles here, as surely benefiting from genetic research in non-pecuniary terms is supported. Commercialisation might also have negative impact in terms of conflicting with the (supposedly) more altruistic scientific and medical motivations.

If genetic material is priceless, non-commercialisable how can it be calculated? If it is 'sacred' how can it be sold? There remains the possibility of a gift but gift relationship has specific characteristics that present commercialisation atmosphere seems not to support. The case for gift relationship was famously stated by R.T.Titmuss who developed this approach in specifically moral terms[77]. Titmuss studied the blood services and compared the donor-based approach of the United Kingdom to the paid-for services of US (and Japan). He was interested in:

> “*the extent to which specific instruments of public policy encourage or discourage, foster or destroy the individual expression of altruism and regards for the needs of others./…/ we wanted to know whether these instruments or institutions positively created areas of moral conflict for society by providing and extending opportunities for altruism in opposition to the possessive egoism of the marketplace*.”[78]

His conclusion stated that the market in health care is an economic and moral failure. The donor-based British system provided more sufficient and better quality blood than the US services where donors/sellers were paid. Titmuss’ explanation stressed that paid-for services actually removed choice as *“the opportunity to behave altruistically — to exercise a moral choice to give in non-*

---

[74] Jürgen Habermas, “The Debate on the Ethical Self-Understanding of the Species,” in *The Future of Human Nature* (Cambridge: Polity, 2003): 71.

[75] A good overview of consequentialist and non-consequentialist arguments against gene patenting can be found at Ruth Macklin, “The Ethics of Gene Patenting” in *Genetic Information. Acquisition, Access, and Control*, eds. A. Thompson, R. Chadwick (New York: Kluwer Academic/Plenum Publishers, 1999): 129–138.

[76] David Resnik, “The Morality of Human Gene Patents,” *Kennedy Institute of Ethics Journal* 7, 1 (1997): 43–61.

[77] Richard Titmuss, *The Gift Relationship: from human blood to social policy* (London: LSE Books, 1997).

[78] Ibid.,59.

monetary forms to strangers"[79] was unavailable. The market corrupted this moral relationship of gift-giving and of freedom to give, transforming altruists into self-seekers[80]. Titmuss deemed the economic sphere of social relations incapable of satisfying the many human needs, and indeed economy was actually responsible for the creation of a number of "diswelfares'[81].

The applicability of gift-relationship in genetics has been discussed[82], and in smaller research projects it has been shown to play an important role. But the special moral understanding underlying the gift-relationship — the voluntariness, the somewhat equal standing of partners, is not present in the current global research situation. It is necessary to consider seriously the possibility that medical research itself has changed considerably and is consequently not an arena of altruism it perhaps used to be. Indeed, I think it is not too far-fetched to insist that the profits of pharmaceutical companies are at this juncture the most guaranteed benefit of the entire genetic endeavour, and this even if the many health-related hopes will remain unfulfilled. And thus it seems hypocritical to the extreme to suggest the centrality of gift-relationship to the many developing countries and it is also questionable approach in pharma-led research projects in the industrialised countries. Non-engagement with the benefit-sharing issue is an option that only some can afford and not so for populations or communities already in the midst of genetic mining.

But healthy pessimism towards benefit-sharing seems to be justified in many cases where the potential outcomes of genetic research seem to be effortlessly likened to the naturally occurring resources (oil, gold etc) that are taken for granted. In reality we are presently dealing with the hyped potentiality and the sharing of even most exquisite promises is simply too far-fetched and naive. Benefit-sharing discussions also tend to monopolise the problematic side of genetic research and actually exclude significant other issues. Sociologists of medicine have underlined the important questions of power, agency, knowledge, personhood, risk and responsibilities that genetics has increasingly promulgated[83]. Benefit-sharing does

---

[79] Ibid.

[80] Julian Le Grand, "Afterword," in *The Gift relationship: from human blood to social policy* (London: LSE Books, 1997): 334.

[81] Martin Hewitt, *Welfare and Human Nature. The Human Subject in Twentieth Century Social Politics* (New York: MacMillan, 2000): 61–63.

[82] For example Helen Busby, "Blood Donation for Genetic Research: what can we learn from donor's narratives?" in *Genetic Databases. Socio-ethical issues in the collection and use of DNA,* eds.R.Tutton and O.Corrigan (New York: Routledge, 2004): 39–56.

[83] See for example Anne Kerr, "Rights and Responsibilities in the Genetics Era," *Critical Social Policy* 23, 2 (2003): 208–226; Ann Robertson, "Biotechnology, Political Rationality and Discourses on Health Risk," *Health* 5, 3 (2001): 293–309; Carlos Novas and Nikolas Rose, "Genetic Risk and the Birth of the Somatic Individual," *Economy and Society* 29, 4 (2000): 485–513; Nina Hallowell, "Doing the Right Thing: genetic risk and responsibility," *Sociology of Health and Illness* 21, 5 (1999): 597–261.

not solve, or in most cases even relate to these issues, not to mention that human health and well-being is only partially dependent on genetics.

Keeping in mind the abovementioned reservations towards benefit-sharing, I will argue however, that discussions of benefit-sharing are necessary even if one disagrees with the underlying trends of commercialising the genome, as closing ones eyes to a certain existing and increasingly powerful “evil” does not make it disappear. The exercising of gift-giving or altruism requires particular preconditions that are presently not available.

CHAPTER 2.
ARGUMENT THROUGH SOLIDARITY

This chapter will focus on the concept of solidarity as a possible rationale for benefit-sharing. Solidarity is an elusive notion that cannot be neatly categorised although most would agree that it characterises indeterminate feelings of closeness and perhaps of even caring in relation to the interests of group of other people. One of the ways in which it has often been conceptualised is as an alternative to rights-and-justice-based liberal discourse and is therefore very much identified with communitarianism. The latter is a social and political philosophy that claims centrality to the collective values in comparison with liberal theories that focus on the significance of the individual, her independence, autonomy and rights. Solidarity is by definition a collective notion, only possible among others and thus often associated with communitarianism.

I will argue that the elaboration of the notion of solidarity is necessary if it is to be employed successfully in benefit-sharing discussions. Solidarity as identified in communitarian discourse would be a suitable principle for specific benefit-sharing that focuses on a certain limited community or population. But if solidarity is an argument for pursuing universal benefit-sharing to provide access to the results of human genetic research to the majority of the world population, then this notion needs to overcome certain limitations that characterise it within communitarianism. My objective in the following chapter will be to argue for a wider and more complex understanding of solidarity, showing the relevance of this notion also in liberal frameworks and in relation to the concept of justice.

2.1. Liberalism versus communitarianism — an outline of a debate

The political philosophy of the past few decades has been much involved in debating the watershed between communitarian and liberal theories. This is illustrated by the academic discussion that followed the publication of an influential book — "*A Theory of Justice*" — by John Rawls[84]. Rawls explicated a liberal political theory arguing for certain principles of justice that should guide the setup and functioning of basic social institutions. The response, in the form of criticism, analysis and further elaboration has been significant[85]. Little

---

[84] John Rawls, *A Theory of Justice* (Cambridge: Harvard University Press,1971).

[85] Robert Nozick attacked Rawls' *Theory of Justice* from a libertarian point of view in his *Anarchy, State, Utopia* (Oxford: Blackwell, 1975); Susan Moller Okin applied a critical feminist perspective in her *Justice, Gender and the Family* (New York: Basic

of what has been written in political philosophy post-Rawls, can do away with the non-engagement of the ideas and ideals that he proposed.

One of the most systematic and significant responses to Rawls has originated from philosophers commonly referred to as communitarians[86]. While this label certainly does injustice to the complexities contained within these diverse approaches, there are certain core elements of communitarianism that can be outlined, especially in comparison with the liberal theories it opposes. It is useful hereby to map out some basic divergences between liberal and communitarian approaches[87].

1) The problem of the self. Liberal theorists posit the autonomous, independent being at the centre of moral and political theory, whereas communitarians argue for the substantiality of human dependence and affirm co-existence as central. In other words, the notion of dependence that is pushed aside and rather construed as a negative characteristic within liberal doctrines, is by communitarians argued to be necessary, beneficial and ultimately self-constituting. The latter thus argue that the development of the self is fundamentally linked to the fact of our social embeddedness, our co-existence with and dependence upon others, and the liberal vision of an autonomous individual is a mistaken or even harmful fiction.
2) The relationship between the right and the good. Liberals have mostly insisted on the possibility of detaching these two, at least to some degree. The right is usually identified with considerations of justice. The good is a short name for referring to possible versions of the good life, to the multitude of values that are central in giving meaning to life and providing opportunities for happiness. For example liberals perceive law as the practical embodiment of the right that is a neutral sphere where different versions of the good life can be adhered to in a pluralist society. Liberals therefore argue that the right is only responsible for setting up certain political values and rules and allows for a wide (preferably individual) choice in the selection of a good life. Communitarians object to the conceivability of disengaging the right and the good and argue that the

---

Books, 1989).; Norman Daniels has applied Rawls within health care: *Just Health Care* (Cambridge: Cambridge University Press, 1985).

[86] For example Michael Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (Oxford: Blackwell, 1985); Michael Sandel, *Liberalism and the Limits of Justice* (Cambridge: Cambridge University Press, 1982); Alasdair MacIntyre, *After Virtue: A Study in Moral Theory* (London: Duckworth, 1981); Charles Taylor, *Sources of the Self. The Making of the Modern Identity* (Cambridge: Cambridge University Press, 1989).

[87] I rely here on a useful analysis of Rainer Forst in *Contexts of Justice. Political Philosophy beyond Liberalism and Communitarianism* (Berkeley: University of California Press, 2002).

liberal account of the supposedly neutral right already privileges certain versions of the good life and discriminates against others.

3) The ethical status and context of the political community. In liberal thought the notion of individual autonomy is central for ethical and political life. For example Rawls' political conception of a person is primarily defined through individual-centered qualities like the capability and freedom to have a conception of the good, to be the self-originating source of valid claims and to take responsibility for one's ends[88]. Individual rights have the priority before the common good. For communitarians common political action, solidarity and self-governance are not only instrumental in achieving social goals but also intrinsically valuable. They argue that participation in common practices and policies is constitutive and affirmative of the self and necessary for individual flourishing and virtuous character[89]. While there seems to be an inherent confrontation between the individual and the community in much of liberal writing, communitarians are rather focusing on the positive aspects of this relationship — individual good is a necessary component of and develops through the common good.
4) Universalism and contextualism. Liberals argue for a set of basic rules with wide applicability that should map out and guarantee a certain political and legal structure. For example human rights should be respected and protected universally and it is their very rationale to be independent of any local context. Communitarians suggest that disregard for context cannot be justified as it actually means the prioritising of certain values (clothed in the language of supposedly neutral laws) before others. For example some communitarians are of the view that universal human rights discourse or even the rights discourse in general is simply a powerful conceptualisation of one political viewpoint, that of liberalism and there is little universal about it.[90] Communitarians are of the opinion that context gives meaning and it is unethical to attempt to apply universal rules that disregard the local practices and traditions.

Needless to say, the above is a sketchy and decidedly crude outline of a very complex discussion. But certainly some of the distinctions can be debated also on this very fundamental and even adversarial level and I will be returning to some of those dichotomies repeatedly throughout this chapter.

It seems plausible to suggest that solidarity has mostly been viewed as a group-based quality, be it small scale workers unions, extensive party-politics or even

---

[88] John Rawls, "Justice as Fairness: Political not Metaphysical," *Philosophy and Public Affairs* 14, 3 (1985): 239–244.

[89] Often communitarian thinking is closely involved with the contemporary application of virtue-ethics in political and social theory (for example in the writings of Alasdair MacIntyre).

[90] See the discussion in section 3.5.3, that details some of these arguments.

nation-based affections. But does solidarity in these instances mean the same thing? Or is it a convenient way of referring to certain vague "us" feelings? If so, then in delineating "us" there necessarily must be "them". This hint of certain limits in the very definition of solidarity poses a problem concerning wider applications of solidarity that are relevant from a benefit-sharing point of view. The elaboration of the concept of solidarity is also necessary if this notion is to be applicable in the global context as traditionally solidarity has been associated with a close-knit fellow-feeling or with associations based on shared interests and dependencies. As I will argue below, the concept of solidarity within a universal benefit-sharing framework needs to acquire additional content for it to function on that level.

2.2. Defining solidarity

Solidarity, emerging into English via French from the Latin *solidum* (whole sum), is according to Webster's dictionary defined as "*unity (as of a group or class) that produces or is based on community of interests, objectives, and standards.*" This does not seem to reveal much since the interests and aims of humans are very central to many concepts of political and moral philosophy. Solidarity is an appealing notion rhetorically but ambiguous as to the real substance. One of the central questions in social sciences "How is society possible?[91]" has mostly been answered with references to solidarity that is dependent upon political power, economic exchange relations and cultural value systems. Matti Häyry has defined solidarity as "communal form of altruism" with strings of sympathy, universal benevolence and justice attached[92]. This insists that distinct philosophical approaches articulate this notion differently — in utilitarianism there is the duty of benevolence and egalitarian considerations, in liberal theories the requirement of justice of the rational decision-maker and in communitarianism a mix of mutual dependence and psychological sympathy[93]. Can all those considerations really fit under the single umbrella of solidarity?

In principle it is possible to employ a particular definition of solidarity within a specific theory, providing for a number of possible understandings of the concept. As I will argue below, for example within a justice-based approach, solidarity can be defined as rational reciprocity (relying on some sort of hypothetical contractual arrangement). Communitarians would probably

---

[91] After the influential article by Georg Simmel, "How is Society Possible?" *American Journal of Sociology*
16 (1910–11): 372–391.

[92] Matti Häyry, "Precaution and Solidarity," *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 202.

[93] Ibid., 202–203.

disagree — solidarity is rather an outcome of a realisation of our interdependence, arising from some sort of descriptive ontology. To clarify I have below categorised what I take to be the major lines of thinking behind solidarity.

2.2.1. Solidarity as contract

Contractual solidarity can be historically linked to political activism of the social democratic type. For example, in trade unionism the shared objectives regarding working conditions and pay provided the collective rationale for solidarity. This reciprocity was contractual in a sense that all were expected to contribute to the common cause (in terms of time, experience, money etc). To ensure success in the pursuit of shared important objectives, solidarity presumed complaisance from one side and created dependencies on the other. In other words, solidarity was characterised by more or less uniform observance of agreed policies on the one hand and the internalised acceptance of the necessity of achieving the stipulated common goals on the other.

This perspective on solidarity has been much researched by sociologists, who have discussed the notion of solidarity for a considerable time[94]. Scarcity is a significant notion here, as it is viewed as a basis for dependence that grounds solidarity-based behaviour[95]. In other words, solidarity is an outcome of rational choices that are made to secure certain goods, services etc that are in deficit. Solidarity is essentially linked with "groupness", it measures the capacity of the group to influence its members[96]. Michael Hechter has theorised principles of group solidarity in the following vein: group rules are fulfilled because of an obligation, obligation is backed up by control capacity on the one hand and dependence on the other, so as to ensure that all members comply — and only then is solidarity achieved[97]. This analysis seems reasonable as a type of contractual solidarity in case of smaller groups. But the larger the group, the more difficult and costly it is to retain control capability over group members — what is easy to do within a credit association or even a political party, is much more difficult to attain in more loose social groups. Because the controls are

---

[94] Bronislaw Malinowski, *Argonauts of the Western Pacific*, London: Routledge & Kegan Paul, 1972; Marcel Mauss, *The Gift. Forms and Functions of Exchange in Archaic Societies*, transl. by I. Cunnison (New York: The Free Press, 1968).

[95] Turner and Rojek have conceptualised scarcity as a function of social closure and consequently the structure of social action is being defined in terms of the dynamic between the scarcity and solidarity. *Society and Culture,* xiv.

[96] Michael Hechter, *Principles of Group Solidarity* (Berkeley: University of California Press, 1987): 8.

[97] Hechter even offers an equation for measuring solidarity *solidarity= f (ab),* solidarity is a function of a(extensiveness of group obligations) and b (rate of compliance to obligations). Hechter, *Principles of Group Solidarity,* 10–11, 18.

weak, compliance within larger groups is problematic, or at least alternatives to some central control capability must be found.

Perception of solidarity as a contract is in philosophy related to liberal theories, more specifically to the notion of justice arising from an understanding that it would be rational to accept and legitimate the obligations of solidarity[98]. This type of contractualism begins with Thomas Hobbes' fictional agreement that self-seeking individuals conclude to secure their wellbeing[99]. Such agreement becomes a possibility when people living in the state of nature (where *homo homini lupus est)*, accept the constraining of their hitherto unlimited liberties in exchange for protection. Contractual solidarity is a necessity, crucial for the chance of survival. Hobbesian contract is a prime example of the double-sided character of solidarity, of a necessary mix of complaisance and dependency that is a result of rational, egoistic contemplation.

Little over century later Immanuel Kant provided a different rationale for accepting the reciprocal duties. Kant insisted that rational persons accept their duties towards each other out of respect for moral law[100]. Thus not selfishness but a rational acceptance of the requirements of morality, our duty as human beings to adhere to the categorical imperative, is the basis upon which human co-existence should stand. The most well-known formulation of the categorical imperative insists that one should always act so that the maxim of a chosen action could be wished to become a universal law. For example if I choose to lie, I would have to willingly accept that lying will become a universal law. According to Kant however, humans as rational agents cannot possibly agree to such a course of action. Reciprocity that is based on our acceptance of these moral rules is central to this form of solidarity.

The most well-known contemporary example of contractualism is elaborated by John Rawls. In the context of our discussion, he argued that rational, egoistic individuals would agree to a hypothetical contract behind the veil of ignorance that details a set of principles of justice to govern the society[101]. Veil of ignorance would hide from those in the original position information about their own characteristics in the society (sex, class, wealth, capabilities etc). Therefore our ability to imagine ourselves in various difficult positions would result in our

---

[98] Despite the shared contractual formula, in comparison with the sociological approach, the explanation of solidarity within liberal theories has a somewhat opposite direction. When the former measures solidarity in terms of the capacity of the group to influence the behaviour of a member (intentionality from the group to the individual), then liberal understanding of solidarity is defined through individual's (chosen) attachment to a group.

[99] Thomas Hobbes, *Leviathan,* ed. R.Tuck (Cambridge: Cambridge University Press, 1996): esp.117–121 (2,17).

[100] Immanuel Kant, "Groundwork of The metaphysics of morals," in *Practical Philosophy*, trans. and ed. M. J. Gregor (New York: Cambridge University Press, 1996): 37–108.

[101] Rawls, *Theory of Justice*, 118–123.

acceptance of the principles of justice that form the core of his contractual theory. This is a form of social contract theory, where solidarity is "a social and cultural infrastructure for justice"[102], an environment that is based on the accepted equality of the members of society and where solidarity is indispensable to buttress the furthering of common goals and to provide support in times of stress and hardships. Rawlsian solidarity is a complex notion, inclusive of an egoistic thinking as well as resultant of our ability to identify ourselves with the hardships and difficulties of others.

What is common to those three theoretical treatments is their reliance on rationality as the central motivating element in human behaviour and as a basis for solidarity. However, this type of solidarity is challenged by egoistic behaviour of certain members — an issue that is known as the free rider problem in the rational choice theory. Rational choice theory is an approach that tries to predict human behaviour based on the premise that individuals act rationally — calculate the costs and benefits of alternative actions and are motivated to increase their gains and decrease losses. Rational choice theory has been very influential especially in economics but is also widely employed in social theory and reflected in much of liberal political philosophy that is centred on the choices of a rational individual.

Free-riding characterises behaviour where services or goods are taken advantage of without returning payment, devoting effort or contributing otherwise. Free-riding is mostly associated with public goods, where it is complicated to identify this behaviour as plain stealing. Public good is usually defined as a being non-rivalrous (e.g. my using of this good does not decrease the availability of this good to others) and non-excludable (no-one can be excluded from using this good)[103]. Solidarity can also be conceptualized as a public social good.

If benefits can be obtained without fulfilling obligations then rational agents would choose to free ride, and in sociological experiments this has been somewhat confirmed[104]. Why would a rational agent take on extra burdens if it is possible to enjoy a certain good without individual contribution? But if everyone would think and act this way, then of course there would be no public social goods like solidarity. The fulfilment of the implicit contract is based on trust but overall solidarity is threatened if the fact of free-riding becomes public.

Rationality-based concept of solidarity cannot offer a complete explanation for the existence of solidarity. There is something missing in the account of human actors as rational self-interested individuals. Trust necessary for social

---

[102] Rob Houtepen and Ruud ter Meulen, "New Types of Solidarity in the European Welfare State," *Health Care Analysis* 8, (2000): 336.

[103] Ruth Chadwick and Sarah Wilson, "Genomic databases as global public goods?" *Res Publica* 10, 2 (2004): 123–134.

[104] A list of relevant studies in given in Hechter, *Principles of Group Solidarity*, 27,fn 15.

action and the normative frameworks of duties and obligations cannot be explained solely through rational considerations. Rational choice theory and also liberal political philosophy that take the society to be simply a multiplied version of an individual, fail to perceive social action as a qualitatively different concept. Unintended side-consequences, (or externalities in the language of economics) as well as non-rational elements have a role to play that cannot be explained through a model of individual rational choice.

Therefore solidarity as a contract between rational agents offers an inadequate understanding of this notion. Or alternatively, the view of rationality as defined in these sociological and some liberal approaches might not do justice to the way people actually deliberate and act. For example Kant would regard free-riders as irrational as he defines rationality through adherence to moral law and not linked directly to self-seeking motivation and behaviour.

2.2.2. Solidarity as benevolence

The second interpretation of solidarity has a different starting point both historically and philosophically and provides therefore an alternative elaboration that stresses benevolence. In philosophy this strand is for example represented by moral sense theories that deny the centrality of self-interest in morality and focus instead on natural human disposition towards the virtuous[105]. Humans are argued to be benevolent and gaining pleasure from virtuous, altruistic behaviour. Emotions, for example our desire for sympathy, can also ground solidarity as part of morality[106].

Benevolence as central in human motivation and crucial in grounding solidarity has been an important aspect in religious thought. In Europe solidarity is closely related to Christian democratic thinking, being based on notions of altruism and sympathy linked to Christian ethics. Concerned with helping those in need, this strand of solidarity is clearly more asymmetrical than the contractual type. The moral obligation arises from the inequality of power between the ones in need and the ones capable of and willing to help. Although solidarity as benevolence would traditionally be based on authoritative requirements of charity that might be enforced by religious commitments, it can encompass also sentiments arising from subjective compassions.

While solidarity as benevolence is certainly a possible way of helping those in need, the essential power asymmetries of this approach are problematic

---

[105] See for example Anthony A.C. Shaftesbury (3rd Earl of), *Characteristics of men, manners, opinions, times*, edited by L.E.Klein (Cambridge: Cambridge University Press, 1999); Francis Hutcheson, *An Inquiry into the Origins of our Ideas of Beauty and Virtue* (Indianapolis: Liberty Fund, 2004).

[106] Adam Smith, *Theory of Moral Sentiments* (Cambridge: Cambridge University Press, 2002).

because of the inegalitarian way the relationship and the roles are pre-defined. This is a relevant concern especially in cases where the needy might feel entitled to justice and not charity. To bring an example from benefit-sharing discussion, it could be argued that benefit-sharing schemes should specifically not be based on benevolence, as this would be degrading to the participants who wish to take part as equal and willing partners and not be the objects of charity. Secondly, solidarity as benevolence threatens to be insufficiently committal because of its ultimately optional nature rendering it unsuitable as the basis for more stringent public commitments. In other words, if benevolence is laudable but optional, it might be inadequate in guaranteeing the necessary practices. For instance benefit-sharing would be dependent on the willingness of those in the position and able to assist but there would be no binding arguments for those who are simply not willing.

2.2.3. Solidarity as recognition of fundamental interdependence

Opposed to the rational contractual approach but also differing from the charity-based benevolence, communitarian thinkers have sought to theorise the concept in alternative ways. A suitable starting point for distinguishing contractual and communitarian accounts can be found in Ferdinand Tönnies' influential descriptive theory of the differences in group attachment[107]. The above discussed solidarity as a contract is illustrated through the notion of *Gesellschaft* that characterises many economic dealings and is close to strands of moral and political philosophy that base relationships on reciprocal rights and duties. The attachments are based on rational decisions regarding self-interest and also recognition of common interests. Communitarians on the other hand, view solidarity as manifested in *Gemeinschaft* that is characterised by obligations rising from affections and emotions, rendering solidarity a realisation of mutual interdependence. There is greater stress on the importance of the common good, but in contrast to liberal theories, this is not necessarily oppositional to private good but in many ways overlapping. Recognition of the fact that people share interests and values forms the basis for solidarity that is conducive for the realisation of these interests and functions to uphold the shared values.

Interdependence is a concept that attempts to contain an understanding that people depend on each other in far greater extent than is recognised by the interactions of rational self-interested persons. This "something" rendered

---

[107] *Gemeinschaft* is usually translated as *community, Gesellschaft* as *society.*Tönnies' context for such a differentiation concerned the rise of modern capitalist society where the attachments of the close-knit community slowly gave way to the competitive, individual-centred instrumental relationships. Ferdinand Tönnies, *Community and Society* (East Lansing: Michigan State University Press, 1957).

invisible by theories that define solidarity as a contract among rational individuals, might well be expressed in the phenomenon of public good.

To continue with the notion of solidarity as interdependence, a good example of this type of thinking in practice is offered by European welfare services. The recognition and the nurturing of the tendencies of social cooperation will not only benefit the people involved but will result in common goods (like solidarity) as externalities. As British welfare thinker T.H.Marshall writes in an oft-quoted passage:

> *"extension of social services is not primarily a means of equalising incomes /…/there is a general enrichment of the concrete substance of civilised life, a general reduction of risk and insecurity, an equalisation between the more and the less fortunate at all levels"*[108].

Solidarity in sense of shared contributions is central to the many health-care systems in Europe where risks are pooled between the old and the young, the healthy and the ill, often including also more controversial lifestyle solidarity[109]- that between smokers and non-smokers for example.

In terms of moral justifications in explaining the necessity of welfare services two opposite approaches are discernible[110]. Firstly the position that welfare is necessary because of the social ethos — welfare as an expression and realisation of common morality and solidarity. And oppositely, a view that perceives national welfare as the prerequisite for achieving social cohesion. Either way the recognition of the commonalities and interdependencies among citizens grounds this version of solidarity more on the side of emotions and affections than the rationality-driven contractual approach[111].

Solidarity is here a jointly enforced agreement built of shared normative values. Problems with this approach lie in the extensive descriptivity of the content of morality. If the entrenched values and ways of living are to be appreciated among other things also simply because they exist, then the grounds for dissenting have been severely limited. Indeed, some versions of communitarianism curtail civil liberties with the purpose of promoting the

---

[108] T.H.Marshall, *Citizenship and Social Class* (London: Pluto Press, 1992): 33.

[109] Margo Trappenburg, "Lifestyle Solidarity in the Healthcare System," *Health Care Analysis* 8 (2000): 65–75.

[110] William Robson, *Welfare state and welfare society: illusion and reality* (London: Allen & Unwin, 1976).

[111] In the history of the European welfare states the tendency has been to move from the charity-based models of the pre-WWII towards the contractually justified models afterwards. But this can also change, as the Swedish experience of the past decades testifies — in times of recession in 1990s "affectionate" solidarity increased in comparison with the more contractual tendencies of the affluent 1980. Åke Bergmark, "Solidarity in Swedish Welfare — Standing the Test of Time?" *Health Care Analysis* 8 (2000): 395–411.

common good[112]. In communitarian version of solidarity the delicate balance between private and common good is sometimes in danger.

2.3. Discussion and the possibility of global solidarity

As discussed above, these three ways of conceptualising the notion of solidarity (solidarity as a rational contract, as benevolence or as recognition of fundamental interdependence) offer rather divergent and often even contradictory possibilities. At the same time it is necessary to acknowledge that the above discussed conceptions are not separated from each other by impenetrable ideological boundaries but that fair amount of overlapping takes place in the actual application of the notion of solidarity. So how should one proceed? Since the overall aim of my work is to shed light on the concept of benefit-sharing, I will analyse the meaning and usefulness of solidarity (or solidarities) in this context. I will mostly examine the relevance and possibility of solidarity on a universal level, and less within specific benefit-sharing frameworks. I do not intend to propose solidarity irrelevant on smaller scale benefit-sharing, it is simply that it is *prima facie* less problematic. This is because I suggest that intuitively people accept solidarity as an applicable concept within smaller, in a sense “graspable” groups and communities but its relevance could be viewed as problematic on a wider scale. Nevertheless, it has been suggested as an appropriate concept universally[113]. What does the application of this usually bounded notion mean on a larger scale?

I will distinguish three important aspects to provide the lens to assess solidarity within benefit-sharing and also to argue which type of solidarity is best suited for engagement within this framework. Firstly there is the question of the motivational basis for solidarity and whether rationality or emotions ground our attachment. Secondly, I will deal with the possible limits of solidarity — as often this notion implies a necessary *us* versus *them* stance. Thirdly, the subject matter of power inequalities and its relevance in solidarity shall be examined.

2.3.1. Motivation for solidarity — based on emotions or rationality?

Although the three accounts of solidarity I have outlined could be at first glance categorised into either emotions- or rationality-based groups, I would suggest

---

[112] Some such practices are suggested by Amitai Etzioni, *The Spirit of Community: Rights, Responsibilities and the Communitarian Agenda* (London: Fontana Press, 1995): 163–206.

[113] Ortúzar, “Towards a Universal Definition”; Shrecker, “Benefit-Sharing in the New Genomic Marketplace”.

that all three need both emotions and reason to ground solidarity, albeit in different degrees.

For example as regards contractual solidarity, I think we have feelings about our rational decisions and the positions we hold, and vice versa, it is natural for us to try to reason about our emotions and attachments.

It is an ongoing discussion in philosophy as well as in political and social life, as to why our rational convictions regarding certain morally needed actions do not lead to our fulfilment of those actions[114]. If we are assured that everyone has the right not to starve involuntarily, why do we not act upon that creed to ensure such a right? Naturally, I do not intend to suggest that we never act based on rational decision-making but it seems that in many cases we do need the extra emotional incentive. Witnessing suffering visually for example through TV is more likely to propel us to action, despite the fact that this might not have actually added to our previous knowledge. Similarly, acting solely upon affections is rare as we also try to find rationality-based reasons to buttress our feelings. This suggests that the traditional way of dichotomising these two elements in either/or form could be misguided. The stronger our resolve to do something, the more likely that both reason and emotions are involved.

In arguing for the recognition of the moral significance of emotions, one argues in philosophy essentially against Immanuel Kant[115]. Because Kant links morality so strongly with rationality-based action, he simultaneously dismisses the ethical relevance of emotions, affections and inclinations. On the other hand, I do not think that David Hume's position on reason as the slave of passions can be supported without reservations either[116]. His account of human behaviour as resultant of habits, sentiments, conventions and experience accords no definitive role to reason in the selection of ends. Martha Nussbaum takes the middle course of recognising and arguing for the relevance of both in ethical life. I think her position is best equipped for articulating the moral motivation that could be the basis for solidarity on a more universal and inclusive level, outside the traditional community- or even nation-based model[117]. Emotions are at least as powerful in motivating people for action as reason. And although I believe that rational discussions and justifications for universal solidarity and justice can also give rise to emotions, we should not underestimate the moral value of

---

[114] This relates to an ongoing discussion regarding *the weakness of the will* and whether our judgement about a morally commendable action already includes an intention to do this action or not.

[115] Kant, "Groundwork", 37–108.

[116] David Hume, *A Treatise of Human Nature* (Oxford: Clarendon, 1978): 413–418 (2,3,3).

[117] Martha Nussbaum. *Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy* (Cambridge: Cambridge University Press, 2001).

information targeted to our feelings[118]. Also, there is an Aristotelian idea that emotions can be cultivated by a virtuous person[119].

An account that accepts the significance of both emotions and reason is best equipped for grounding the notion of universal solidarity. Therefore both contractual and communitarian solidarity are possible simultaneously and can be complementary ways of supporting this notion. While rationality can ground our recognition and respect towards the rights of people (not to be exploited, to have access to health care etc), emotions are often necessary in triggering us to take action, change our practices or, in short, act on our moral judgement. This complementarity is further highlighted by an understanding that the very possibility of a contract actually presupposes the existence and recognition of certain shared values that need to precede any agreement[120]. Shared values are not only the basis of communitarianism but also the core of liberal theories. Rationality itself does not need to be a value-free zone as Weber's differentiation between *Wertrationalität* (value rationality that characterises the attachment to the dominant moral system) and *Zweckrationalität* (instrumental, utilitarian rationality) demonstrates[121]. The relationship is not one of opposites and possibly it is not even a continuum with rationality at one and emotions at the other end. In most of our actions these two are fused in a more complex manner than would be allowed by this two-dimensional schema. Thus the question whether global solidarity will have to rely on rationality or emotions is a wrong one. It will need both.

2.3.2. Us versus them — on the limits of solidarity

Traditional definitions of solidarity (recall the "communal form of altruism" from the beginning of the chapter) have centred on a certain community or group of people, be it the old communist class-based calls for the solidarity of the proletariat or the solidarity of a close-knit family. *Us* versus *them* stance is perhaps most visible in communitarian type of solidarity but it is also relevant in solidarity as a contract as it excludes those not participating in the contract (e.g. the implicit contract that is assumed to ground solidarity among citizens of the same country to the exclusion of others). Is not solidarity by definition then

---

[118] Of contemporary thinkers Richard Rorty is continuing the tradition of upholding sentiments as the basic foundation of moral motivation.

[119] Aristoteles, *Nikomachose Eetika,* trans. and ed. A.Lill (Tartu: Ilmamaa, 1996), esp. Book II.

[120] See Emile Durkheim on the non-contractual elements of contracts. *The Division of Labour in Society* (New York: Free Press, 1997):149–75.

[121] Max Weber, *Economy and Society: An Outline of Interpretive Sociology,* trans. and ed. by G. Roth and C.Wittich (Berkeley: University of California Press, 1978): 24.

always also assuming those who are outside the group we are in solidarity with? Does not solidarity depend on a necessary confrontation between us and them? This is an important question that might turn the notion of global solidarity into an oxymoron. Can we in principle be in solidarity with everyone or almost everyone?

I think especially communitarian type of solidarity might be hindered in its potential wider applications by this aspect. As shared attachments and traditions are taken to be the necessary basis for solidaristic affections and behaviour, even the descriptive fact of value pluralism and relativism in the world suffices to limit this type of solidarity. If our identities and aims are intimately linked and dependent upon the differences with others it is increasingly difficult to overcome this self-constituting aspect to embrace the goals of others.

Here I think it would be useful to differentiate between two aspects within communitarian thinking. Firstly a rationale that is exemplified by some elements within identity politics. Identity politics is a type of ideology and practice where the marginalised and/or oppressed groups within society organise themselves around their shared identity that is seen as a basis for their marginalisation. The opposition that is set up between us and them is highlighted as a necessary component of the very construction of an identity and therefore the adversarial character of the relationship is rather strong.

This aspect of communitarianism does not seem to be suitable for grounding the project of global solidarity.

The second perspective, offering a possibility for a more inclusive and wide-ranging solidarity, lies in the notion of interdependence that has increasing relevance in our era of globalisation. The arch-example of such interdependence is of course the environmental state of the world. But the global economic structures and international trade are similarly integrating the far-away corners of the world into one big marketplace. The populations of the affluent countries are increasingly informed of the ways in which their everyday fresh groceries and cheap garments link them to the workings and hardships of the populations in less developed areas. Global public health issues appear daily in newspapers as diseases (e.g. SARS, AIDS) spread across the world and underline our common vulnerabilities. As this interdependence is further realised, it might have the potential to evoke both reasoning and emotions to ground solidarity on a more global scale. However, in evoking such grand ideals one should be very careful in recognising the very unequal power relations that characterise interdependence in our world.

2.3.3. Power inequalities

Power inequities are a very visible part and parcel of the global situation[122]. The dependencies are complex and certainly not one-way. The developing countries depend on the investments, aid and know-how of the developed countries but the latter need the resources, labour and products of the less developed ones. Nevertheless, the stark differences in negotiating power are a very significant part of that dependence. The world is interlinked but in an unequal way. How is this inequality reflected in and influencing the possibility of solidarity? In sociology these two are very much connected — a group has to have an influence on members' behaviour to ground solidarity (if there is no influence there is no group and therefore no solidarity). How realistic is it to talk about solidarity on global scale if influence and dependence, as pre-requisites for solidarity are so unevenly distributed? Charity is an example of this type of solidarity where power differences are central but benefit-sharing is a concept that attempts to go beyond relying on mere benevolence.

According to Emile Durkheim, solidarity in larger groups (of modern societies) is achieved through attachment to doctrine, that is not based on egoistic calculus of exchange and reciprocity but rather on the convergence of shared idea(l)s that are not questioned by individual members[123]. It is more an engagement with values and less with tangible interests. In a way, this is somewhat surprising because this view argues that value-based solidarity is capable of functioning on a larger scale than interest-based, more instrumental one. Religious affiliations would be examples of this kind of value-based solidarity although faith does not presently seem to have the potential to back a global solidarity.

Since group control seems impossible and indeed non-desirable on this level, there would need to be a doctrine that is voluntarily adopted by people to be a basis for large-scale solidarity. Solidarity would need to be based on universal notions or shared values that should also make sense in local contexts. Also, if solidarity is to extend outside the unequal charity frame, it needs a basis that acknowledges and upholds equality of those involved regardless of actual contingencies and existent inequalities of power. The basis for such equality has traditionally been grounded in notions of human dignity[124], autonomy,

---

[122] Without further inroads into the extremely complex and contentious subject matter of power, I would like to clarify its content for the present purposes. I use the term power here to signify a capability to influence. This includes political, social and economic power as well as that of psychological authority. Power is always relational and my main focus will be on the equality-inequality axis of that notion.

[123] Emile Durkheim, *Division of Labour in Society,* trans. G.Simpson (New York: The Free Press, 1968).

[124] Human dignity is by no account a clear concept itself. Matti Häyry outlines at least five possible and contradicting interpretations in bioethics alone in "European Values in Bioethics: Why, What and How to Be Used?" *Theoretical Medicine* 24 (2003): 199–214.

capability for moral choice and other positive and uplifting qualities. But the shared foundation for equality can also lie in the frailness and vulnerability of the body that arises from the human openness to psychological and physical damage[125]. Solidarity can then be both an affirmation of the highest human potential as well as a platform that guarantees a basic minimum against the hardships and ill fortunes of an actually lived life. Either way recognition of a value of equality is central to overcoming and overlooking the factual inequalities of power.

2.4. Justice and solidarity in benefit-sharing

In bioethics literature solidarity has recently been articulated as a distinct value that fits the European context better than the supposedly American notion of justice[126]. The latter is viewed as too individual-centred and disregarding towards the social and communal aspects of life. The question is whether justice and solidarity really are alternatives, or whether they are partly overlapping or even complementary? In the context of benefit-sharing I will argue for the latter.

Solidarity is not necessarily at odds with individualism[127], although a common perception would readily identify the former with collectivism and thus suggest a necessary incompatibility. While individualism has been perceived as the main culprit in generating "moral decay" and in general weakening the social ties and reciprocity, it might also be argued that individualism is a shared value that needs solidarity in order to be collectively appreciated and upheld[128]. Individualisation can thus be redefined as a new way of shaping social relationships and not necessarily as a opposing these

---

[125] Turner, Rojek, *Society and Culture,* 125.

[126] Rob Houtepen, Ruud ter Meulen, "Justice and Solidarity in Priority Setting in Health Care" *Health Care Analysis* 8 (2000): 327.

[127] In empirical terms this is illustrated for example by research on European welfare states where despite the growth of individualisation, stress on private responsibility, market incentives and the like, the overall support for solidarity-based welfare system is still very high. Ruud Meulen (Final Report of the 4th Framework Programme project), *Solidarity and Care in the European Union*, 2000); available from http://europa.eu.int/ comm/research/biosociety/research_projects/fp4_bio_projects_en.htm; accessed April 20th, 2005). On the other hand, tensions between the rather paternalistic welfare system and the individualistic discourse of patient rights are bound to create difficulties in balancing the justification and practice of welfare regimes. See Tuija Takala, "Justice for All? The Scandinavian Approach," in *Medicine and Social Justice: Essays on the Distribution of Health Care*, eds. R. Rhodes, P. Battin, A. Silvers (New York: Oxford University Press, 2002): 183–190.

[128] Houtepen, Meulen, "New Types of Solidarity", 336–337.

relationships[129]. Moreover, solidarity can be viewed as requiring a precondition of authenticity and responsibility in one's actions (the very core of individualism) because solidarity is based on the existence of and cooperation between acting subjects. Various possibilities exist for reconceptualising the relationship and convergences between justice and solidarity that open up meaningful opportunities in benefit-sharing discussion.

David Miller's account of justice as relational is an example of an attempt to fuse justice and solidarity concerns[130]. Miller's theory has some of its starting points in Michael Walzer's pluralist justice in a sense that he utilises several principles of justice and does not trump one over the others[131]. Walzer has maintained that different principles of justice should guide the distribution of different goods, meaning that not all benefits and burdens should be apportioned according to the same rules. If distinct rules and procedures were employed in different spheres then inequalities in one area would not lead to the (same) inequalities regarding the same persons in another. Miller's account however shifts the focus from various spheres of social existence to its relational aspects. He has linked personal relationships with an account of justice by connecting different principles of justice with specific relation. Therefore merit is a basis for distributive decisions in business dealings, need in familial relations and equality in the public sphere of citizens. Traditionally some of these relationships have been defined through justice, some through solidarity but Miller demonstrates how these concepts can be complementary or at least assessed within the same framework.

Solidarity and justice are both overlapping as well as having their own space. There can be fair amount of overlapping in cases of solidarity towards our fellow citizens in social and legal context[132]. For example needs-based relationships (like those in the health care system of welfare states) can be conceptualised both in terms of justice and solidarity. On the other hand, certain relationships, especially those based on rights, are traditionally considered to belong to the sphere of justice. In the previous section I suggested that in order to overcome the rampant global inequalities in power, solidarity would need to be based on some sort of egalitarian framework. The best candidate here is of course the human rights discourse but that is often identified as a subject matter of justice. Nevertheless it can be argued that people can be in solidarity with respect to human rights.

---

[129] Meulen, *Solidarity and Care in the European Union,* 15.

[130] David Miller, *Principles of Social Justice* (Cambridge: Harvard University Press, 1999).

[131] Michael Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (Oxford: Blackwell, 1985).

[132] Although justice and solidarity can also conflict as when solidarity with someone results in injustice to others. Rainer Forst, *Contexts of Justice,* 304, n.22.

It has been suggested that one way of separating solidarity and justice would be to distinguish between the universal applicability of justice and only local, contextual relevance of solidarity[133]. But this approach would unnecessarily confine the concept of solidarity, essentially identifying it with the communitarian version. It is also insensitive to the differing ways of defining and implementing justice. As Miller's account demonstrated justice can be a relevant category both universally as well as intersubjectively. Both solidarity and justice are rather accommodating notions and in benefit-sharing context the potential of both of these should be preserved.

In benefit-sharing both solidarity and justice are applicable concepts. For example, solidarity has been called for in sharing the benefits of research also with those who have not participated in research. Those who have participated can in principle rely on contractual solidarity that can overlap with justice concerns. But since solidarity as a contract is not appropriate in many cases where benefit-sharing is called for, the content of solidarity here should rather focus on sensitivities to interdependencies and shared values.

The more extended is the number of participants in research, the more significant becomes the concept of solidarity in benefit-sharing. For example, the HUGO Statement on Benefit-Sharing insists on the principle of solidarity on several occasions[134]. Firstly there is the group solidarity among those participating in research or sharing genes — benefit-sharing should not be limited to only those who participated as this would be "inconsistent with solidarity". Although the small scale research projects could in principle ground benefit-sharing within traditional medical frameworks (e.g. compensating for risks taken, taking steps to avoid exploitation etc), the fact that genetic information is shared among people means that participation by some will "automatically" involve their families. Therefore reciprocity based on *quid pro quo* reasoning, on mutual correspondence and essentially solidarity as contract, might not be appropriate.

With community or population based research projects the relevance of solidarity increases further and has been most pronounced in arguments for benefit-sharing on universal level. The HUGO statement insists that health should be promoted universally and affluent nations and commercial entities are "to foster health for all humanity"[135]. Fostering health here does not only mean direct benefit-sharing but for example increasing research focus on the diseases that are prevalent in poorer countries, so that the whole of humanity can have access to and benefit from the technology and know-how. Thus in this second instance solidarity covers a much larger ground and it becomes inappropriate to talk about groups when solidarity with humanity is intended. The notion of solidarity that stretches outside the limited obligations of traditional medical research projects is a useful conception to allow for a wider inclusion of those affected.

---

[133] Häyry, "European Values in Bioethics", 207.

[134] HUGO, *Statement on Benefit-Sharing.*

[135] HUGO, *Statement on Benefit-Sharing.*

An interesting and possibly useful aspect of solidarity has recently been theorised through the notion of engagement. The aim has been to reformulate solidarity as an active practice to apply it more successfully than the mere abstract theoretical construction would allow for. *Solidarity as an engagement* is an elaboration of the idea that the acceptance of human interdependencies is a crucial starting point for social action including solidarity. Concepts like "reflexive solidarity"[136] and "participative solidarity" based on citizenship theory are examples of rethinking solidarity as a more open and active concept. As is especially relevant in the context of global benefit-sharing solidarity becomes not only a question of common values but also an issue of common action[137]. Mere awareness and subscription to shared values is not enough, solidarity also requires constant acting out, renewing and redefining of socially significant relationships.

Solidarity is thus a social construction "constituted in action"[138] not individual, nor collective but rather associational. Similarly, modern theories of citizenship have stressed the centrality of active commitment to engagement in sustaining solidarity. It has been suggested that modern solidarity will be ultimately based on the merging of universal human rights discourse and citizenship rights[139]. This seems like an appropriate combination for a type of solidarity that benefit-sharing would need — inclusive of respect towards individual rights as well as attentive to shared identities and affections characterizing our close associations.

2.5. Conclusion

The present chapter has focused on the analysis of the concept of solidarity and examined ways of defining and clarifying solidarity with the aim of applying this notion in benefit-sharing debate. Solidarity is a popular rhetorical device that has in political philosophy most traditionally been associated with communitarian thinking. I have argued that solidarity is also a necessary component in traditional liberal contractualism, albeit somewhat differently defined and understood. Solidarity, to function successfully on a larger scale and to overcome the antagonism within, should include both of these strands of origin. Recognition of the importance of both rational calculus and emotional attachment as well as acceptance of wide-ranging interdependence is necessary for the successful extension of the concept outside the conventional confines of community or nation-state. The close association of solidarity with the notion of justice is also beneficial in allowing the conceptualisation of various concerns in these complementary discourses.

---

[136] Jodi Dean, "Reflexive Solidarity," *Constellations* 2,1 (1995): 114–40.

[137] Meulen, *Solidarity and Care in the European Union,* 13.

[138] Ibid., 12.

[139] Turner, Rojek, *Society and Culture,* 207.

CHAPTER 3. CONSEQUENTIALIST ARGUMENT

Consequentialism is a theory where the moral rightness or wrongness of an act is determined by its consequences. Consequentialist would reason that benefit-sharing ought to be implemented because of the good consequences that this would bring about or the bad results that would be avoided. On the level of a specific benefit-sharing framework the good consequences might be the betterment of the health of the participating community or population, improvement of the health care infrastructure, strengthening participants' negotiating power in determining the research priorities, and perhaps other benefits. On global scale the good consequences that should guide our practices can include the availability of drugs and improvement of health care services and infrastructure to poor populations, eradication of diseases and other improvements.

Negative consequentialism stresses the importance of avoiding harms, for example the increasing gap between industrialised and developing countries in terms of availability of drugs and therapies, the continuing exploitation of the poor communities and populations by the powerful pharmaceutical companies, the skewed research priorities that focus on the diseases of the few well-off etc. I will be employing the well-known argument of Peter Singer from the famine-discussions of 1970s and will analyse its relevance in the present benefit-sharing debate. The focus will be mostly on universal benefit-sharing as Singer's argument grapples specifically with the moral obligations on this scale.

The most contentious issue with Singer's and similar consequentialist arguments in the present context pertains to the question of how much can morality require from us — in other words, are there limits to morality? Does our ability to help create a duty to help? If we have a duty to help (through, for example, benefit-sharing) then how pressing is this duty? And finally, whose duty is benefit-sharing in the universal context?

3.1. Outline of consequentialism

Consequentialism is a theory of ethics that judges the morality of an act based on the results of that act. Accordingly, in a moral dilemma we ought to choose an act that can reasonably be expected to bring along more positive consequences than any alternative course. What counts as a positive consequence? The outcomes can be measured with different yardsticks. Most traditionally consequences are to be weighed according to their utility, hence the expression utilitarianism. I shall be using consequentialism and utilitarianism interchangeably here although I am aware of traditional distinctions between these two (e.g. the latter as one type of consequentialism). They can be used as synonyms for a type of moral theory that judges the morality of an act based on the results of that act.

According to Jeremy Bentham, who coined the principle of utility in his "*Introduction to the Principles of Morals and Legislation*"[140], utility is defined through a tendency to promote greatest happiness to the greatest number — one ought to choose an act that produces most happiness to a maximum number of people[141]. While Bentham defined happiness as a positive value on the scale ranging from pleasure to pain, other qualities (welfare, preference satisfaction etc) can form the basis for moral judgements. For example, one possible way of assessing the outcomes is the utilitarian calculus offered by Bentham that requires the summing of the various characteristics of expected pleasures and pains. He lists intensity, duration, certainty/uncertainty, propinquity/remoteness, fecundity, purity and extent as important qualities of consequences to consider[142]. But Bentham also admits that many of these qualities can only be considered once pleasures and pains come into existence. His admittance refers to a common critique of consequentialism that points to a human incapability to foresee the outcomes. Consequentialism counts only the results of an act as relevant for the moral judgement of that act. But how can a moral choice be made based on wishful thinking, pessimistic or optimistic outlooks, or plain guessing? An alternative deontological approach would rather suggest that our moral choice should rest on things we know and principles we have accepted to respect. Our actions should therefore be judged through considerations of other aspects besides outcomes. For example Immanuel Kant insisted that the relevance of a motive (whether the action was done based on the good will[143]) is imperative in the moral judgment of an act. But consequentialist would suggest that neglect of possible outcomes — negative or positive — is morally very problematic.

Another important characteristic of consequentialism is the centrality of the value of equality. Whatever yardstick we are using in assessing the outcomes, whether happiness, welfare or other, we ought to count these results respecting each individual involved. The happiness of each is equally relevant in assessing the overall rightness or wrongness of an act.

But how do we know the happiness of others? We can attempt to measure this but we cannot exclude that sometimes people's preferences differ quite remarkably. How can I act morally by taking into account the requirement to bring about greatest happiness to the greatest number if I am not aware of what happiness actually holds for others?

---

[140] Jeremy Bentham, *The Principles of Morals and Legislation* (New York: Prometheus Books, 1988).

[141] The principle of greatest happiness of the greatest number actually first appeared in Francis Hutcheson's *An inquiry into the Origins of our Ideas of Beauty and Virtue*.

[142] Bentham, *The Principles of Morals and Legislation*, 29–32.

[143] Kant, "Groundwork", 37–108.

This is a common epistemological critique of the utilitarian position that emphasises our ignorance of the good of others (and often argues that we are therefore entitled to focus on increasing the good for ourselves and for those we know)[144]. The challenges created by this critique are at some times more difficult to overcome than at others. For example in the context of universal benefit-sharing where focus is often on existential issues of life and death, this argument is weaker. Suffering due to bad health or dying of diseases that are in principle treatable is surely a very harmful condition that we can reasonably expect most people to recognise. On the other hand, within specific benefit-sharing, the issue might be more complicated. Benefits in the form of very basic medical help where needed can certainly be defined as bringing about good for those involved. But as discussed in chapter 1, benefits from human genetic research projects do not necessarily have to originate from genetics, nor even health care. Investments to health care infrastructure or capacity-building are examples of possible alternative benefits. Therefore it is important to ensure that the process of defining benefits be an open and inclusive one so that the benefits to be shared be considered relevant by the participating individuals and community.

Consequentialism, at least historically, shares certain traits with positivism — in philosophy a conception that focuses on the relevance of empirical facts and rejects religious, metaphysical or other transcendental information. Consequentialism and positivism are united in their reliance on empirical facts and strive towards practical and applicable knowledge (Bentham's utility calculator can be seen as a prime example of an attempt to provide a scientifically measurable approach to morality). Nowadays positivism usually does not enjoy a reputable status among philosophers. When searching for wisdom or truth, the relevance of contingencies is often denied or at least downplayed. Theorising aims to transcend our contexts. In a sense, this is understandable as the project of justification and clarification that forms the core of much philosophy, attempts to achieve results that are independent of the possibly haphazard and accidental circumstances of reality. This removal of context is sometimes a necessary requirement for the formation of a prescriptive argument that is independent from mere description. If the existence of certain practices would constitute the very justification of these practices, philosophy (and indeed, any critical thinking) would loose an essential argumentative force. Prescriptive arguments are needed to allow for critique against the prevailing practices and to insist that might does not necessarily make right. Otherwise description would suffice as the explanation and vindication. This line of thought parallels the Humean is/ought distinction that disassociates facts and

---

[144] See for example Henry Sidgwick, *Methods of Ethics* (Indianapolis: Hackett, 1982): 431,434; James R. Otteson, "Limits on Our Obligation to Give," *Public Affairs Quarterly* 14, 3 (2000):183–203.

ought-statements[145]. A general complaint towards positivism insists that it never answers the *why* question but concerns itself solely with the *how*.[146] Of course this is also something that positivists agree with — or at least they do not believe that the *why* can be answered any other way than through the empirical, fact based and supposedly value-free knowledge.

Therefore there is a tendency sometimes to claim that outcome-based approaches are somehow non-moral, simply prudent and essentially independent of moral considerations[147]. The scientific approach of early utilitarians (e.g. Bentham) certainly aimed at incorporating the moral judgement by simply assessing factual material (and therefore blurring the fact-value distinction as the moral would simply ensue from facts). On the other hand, seeing things "*as they are*", is a morally difficult thing to do.[148] While Bentham's utility calculator might be one extreme, I argue for a compromise — there is nothing non-moral about paying attention to circumstances, and vice versa, disregard of context might even be considered immoral. Furthermore, the equality of persons in terms of assigning equal weight to everyone's preferences (a central tenet in consequentialism) has often been stressed as the very definition of morality[149]. I will be returning to this issue of relationship between morality and empirical facts in the last section of this chapter, titled "Can implies ought?"

3.2. Lessons from the past

The subject matter of harms of global scale and the relationship of such harms to morality has already been much discussed previously to the era of genetics: I have in mind the debates surrounding the famines of the 1970s and 1980s[150]. Due to widespread natural disasters coupled with political instability, millions of people in Africa but also in some countries of Asia were threatened with starvation. The fact that the suffering was broadcasted over television to the living rooms of the affluent of the industrialised countries transformed the

---

[145] Hume, *A Treatise of Human Nature,* 469 (3,1,1).

[146] Leo Strauss, "Mis on poliitiline filosoofia?" in *Kaasaegne poliitiline filosoofia,* ed. by J. Lipping (Tartu: EYS Veljesto Kirjastus, 2002): 99–139.

[147] See for example W. Aiken, H. La Follette, "Introduction" to *World Hunger and Moral Obligation* (New Jersey: Prentice-Hall, 1977).

[148] Alasdair MacIntyre, "Moral Philosophy: What Next?" in *Revisions: Changing Perspectives in Moral Philosophy*, eds. S. Hauerwas, A. MacIntyre (Notre Dame: University of Notre Dame, 1983): 13.

[149] Amartya Sen, Bernard Williams, "Introduction" to *Utilitarianism and Beyond* (London: Cambridge University Press, 1982): 10.

[150] For a collection of articles devoted to the subject see *World Hunger and Moral Obligation*; also Onora O'Neill, *Faces of Hunger: An Essay on Poverty, Justice and Development* (London: Allen & Unwin, 1986).

subject matter into a globally debated issue. Moral philosophers alongside politicians, economists, celebrities (LiveAid) and ordinary people pondered on what should be the proper reaction to the widespread famines that threatened to kill millions. Questions addressed at the time included the following: What should be the moral response to global need (of food)? How can we succeed in feeding the hungry if it is (or alternatively, is not) morally required? Would it be wrong to feed the hungry because of the possibly disastrous consequences for all involved if the global population growth will not be curbed? Do individuals or nations have an obligation to feed the hungry?

In some respects, many of these issues are strikingly similar to the ones that the concept of benefit-sharing (especially on the universal level) is trying to address. What should be our moral response to address the needs of large poor populations for drugs and therapies that are unavailable to them because of high prices? How can the fruits of biomedical research benefit persons and people who happen to be born in the more deprived parts of the world? Depending on the justification we provide for benefit-sharing in biomedical research, the answer to those questions can coincide with the world hunger debate.

Most arguments dwelling on charity or insisting on certain (human) rights (to be fed, to have access to drugs and therapies) appear to be a rather straightforward parallel to the famine discussion. On the other hand, arguments based on common genetic heritage of humanity and genetic databases as global public goods, would point to important differences. Also, rectificatory arguments that stress benefit-sharing as compensation for used resources or in response to creating risks for the participant community, are based on a different logic from that of the world hunger discourse.

Since in consequentialism the moral value of an act depends on the outcomes, there is also the possibility that the outcomes of practicing benefit-sharing are harmful. Consequentialist should query whether the application of the concept of benefit-sharing really does provide positive results or avoids harms and if this is not so, benefit-sharing would turn out to be an immoral suggestion. From the 1970s we have the argument that feeding the world's starving would ultimately exacerbate the situation for all involved[151]. The saved individuals will reproduce and their progeny will end up in even worse conditions as scarcity will increase while the world population will grow. According to this view, sending or withholding food should be dependent on foreseeable consequences and intuitively charitable acts might turn out to be deeply immoral once possible long-term outcomes are considered. These doomy neo-Malthusian perspectives were at the time often accepted also by those who did argue for feeding the starving on condition that their reproduction be controlled.

---

[151] Garrett Hardin, "Lifeboat Ethics: The Case Against Helping the Poor," in *World Hunger and Moral Obligation*; Joseph Fletcher, "Give If It Helps But Not If It Hurts," in *World Hunger and Moral Obligation*.

The potentially harmful consequences of benefit-sharing in genetic research are a possibility that has so far not been much discussed. In specific benefit-sharing cases that are arranged around determined research projects, there might be a potential danger when the benefit-sharing arrangement becomes an inducement to participation. The circumstances of biomedical research should never become solely dependent on the offerings of the 'highest bidder' because research often involves risks and inconveniences that should also be considered independently of the offerings of the research agency or sponsor. At the same time it should be recognised that communities do have an interest and a right to negotiate the terms of participation.

On a more general level and in terms of universal benefit-sharing, pharmaceutical companies might worry that stringent sharing requirements could endanger the system of intellectual property rights or inhibit research into novel drugs and therapies in general.

If discussion of benefit-sharing initiates doubts regarding the entire set-up of the present global biomedical research system, then indeed the debate might produce unforeseen consequences that could prove harmful to some interests.

A good example of a consequentialist argument relevant also today is that of Peter Singer, originally produced over 30 years ago in the global famine context[152]. He argued that the ongoing suffering and death in the world, whether caused by famine or unjust economic policies of the powerful, should be acted upon in light of the following principle: *if it is in our power to prevent something very bad from happening, without hereby sacrificing anything morally significant, we ought, morally, to do it*[153]. Singer has been much criticised[154] as well as applauded[155] by various strands of political and moral philosophy for this intuitively appealing principle. Singer's utilitarianism in this context is formulated as negative as it focuses on the moral requirement of avoiding bad consequences, whereas positive utilitarianism would insist on our duty to act towards bringing along positive consequences. Singer's principle can

---

[152] Peter Singer, "Famine, Affluence, and Morality," *Philosophy and Public Affairs* 1, 3 (1972): 229–243. Although Singer himself argues that this argument should also be acceptable to non-consequentialists. In his *Practical Ethics* (New York: Cambridge University Press, 1993): 229–34.

[153] This is a moderate version of a principle of preventing bad occurrences. Singer himself endorses also a stronger version which would argue for the sacrificing of something of comparable moral significance, that is, reducing ourselves to the level of marginal utility (leaving us only marginally better off than the starving). "Famine, Affluence, and Morality", 241.

[154] See for example John Arthur who, following a long-established tradition in philosophy, argues that people are morally entitled to give their own rights and interests a preference over those of the others (e.g. the starving). John Arthur, "Rights and the Duty to Bring Aid," in *World Hunger and Moral Obligation.*

[155] Peter Unger, *Living High and Letting Die: Our Illusion of Innocence* (New York: Oxford University Press, 1996).

also be formulated in positive terms, for example in requiring us to maximise happiness if it is in our power to do so (and does not demand extortionate sacrifices). I think that in present context it does not really matter whether this argument is formulated in positive or negative terms. The difference is sometimes stressed, for example in medical ethics, where avoiding harm is a more stringent duty than bringing about good. The principle of avoiding harm is perhaps intuitively more acceptable and easier to concur as a moral rule but at the same time failure in beneficence can be interpreted as bringing about harm (that could have been avoided) and vice versa.[156] For example the harms to be avoided through benefit-sharing could include the illnesses and diseases that could have been prevented or cured if drugs and therapies would have been accessible.

Singer uses the example of saving a drowning child from a shallow pond to illustrate his principle:

> "*if I am walking past a shallow pond and see a child drowning in it, I ought to wade in and pull the child out. This will mean getting my clothes muddy, but this is insignificant, while the death of the child would presumably be a very bad thing*"[157].

This seems rather straightforward and also an easy thing to do but Singer is essentially arguing for the relocation of the charity/duty distinction, requiring supererogatory acts in everyday life. It is almost always in our power to prevent something bad from happening as there is always something bad happening. Traditionally our responses to these bad things have been divided into two camps: those requiring our action and those left up to our benevolence and individual decision[158]. Singer does not make this distinction (or at least argues against the traditional delineation) and raises the issue of boundaries of morality.

---

[156] In a sense this differentiation is also at the heart of the positive versus negative rights debate that I will examine in section 3.3.

[157] Singer, "Famine, Affluence, and Morality", 231.

[158] An interesting dilemma arises in the benefit-sharing context when we include the problem of entitlement definition into the discussion of this moral principle. The principle of beneficence is usually seen to make demands on things we own but if the principle is really stringent and to be taken seriously, then due to our duty to give, we seem to really not own these things anyways (we have to give them away) or at least we are not morally entitled to keep them. From a point of view that many genetic resources have been "stolen" from developing countries, then the demands now made would not be based on the principle of beneficence or duty to maximise utility but rather on rectification of injustice. See Liam B. Murphy, "Demands of Beneficence," *Philosophy and Public Affairs* 22, 4 (1993): 269–270.

3.3. Boundaries of morality

Attempts to limit our moral obligations are part of the standard critique of utilitarianism. For example it is common to suggest that these types of moral theories are alienating as they allow us to be involved in only one life-project — that of promoting good[159]. As there are always bad things happening and often we are in a position to help in some ways, this would ultimately lead to us being constantly involved in the "project" of harm-prevention without a chance to pursue our own individual goals. It can also be argued that limiting morality is essentially an only way to stay moral or strive toward moral existence as such. Otherwise one can always be attacked with the "*why are you not presently stuffing envelopes at Oxfam?*" critique[160], rendering us immoral each time we are involved in something else besides avoiding harm or promoting greatest possible good.

Consequentialist would argue that we ought to act to prevent bad consequences: enforce benefit-sharing in genetic research so that the fruits of development activities reach those who have contributed in some ways or even simply are in need of the resultant drugs and therapies. If what is asked of the well-off are rather small sacrifices to result in a lot of good (saving a life, curing a disease etc), it is intuitive to suggest that this small burden is required. But what if the improvement of the situation or the really serious engagement with benefit-sharing would require more than slight discomfort from those able to help? How stringent is the duty to avoid bad consequences? After all, everyone is aware that it is of course laudable "to do good" but Singer's principle does not leave this optional or dependent on charity. The principle does not state that *if it is in our power to prevent something very bad from happening, without hereby sacrificing anything morally significant, we are recommended to do it.* No, we ought to respond appropriately and charity is no guarantee of a morally required action. While the voluntary redistributive activities of pharmaceutical companies in responding to grave health care needs in developing countries are certainly praiseworthy[161], they are simply a drop in the ocean and cannot adequately influence the quality of public health in long-term. Moreover, charity can be considered morally humiliating, accentuating the inequalities of power and opportunities. This is especially the case when charity is offered instead of fulfilment of requirements of justice that are seen as relevant.

Keeping in mind the millions of people dying of hunger and treatable illnesses every year in the world, the harms to be prevented by widespread

---

[159] A short overview is offered in ibid., 267–292.

[160] Quote from Daniel Dennett, "The Moral First Aid Manual," in *The Tanner Lectures on Human Values*, Vol.VIII (Salt Lake City: University of Utah Press, 1988): 140.

[161] A number of large pharmaceutical companies have distributed their drugs or vaccines as a charitable practice. For example Pfizer, Novartis, Boehringer-Ingelheim. Macklin, *Double Standards*, 165.

sharing of the results of technological and biomedical development are certainly very serious. How overwhelming is our duty to avoid such consequences? How is the linkage between *ought* and *could* negotiated? What is the relationship between duty and benevolence?

John Stuart Mill and his notion of imperfect duties provide one possible answer to this dilemma[162]. Alongside moral obligations that people must fulfil (or they will be punished), exist also:

> "*things which we wish people should do, which we like or admire them for doing, perhaps dislike or despise them for not doing, but yet admit that they are not bound to do it, it is not a case of moral obligation; we do not blame them, that is, we do not think that they are proper objects of punishment*".[163]

Imperfect duties are still duties but lacking the moral and legal urgency and obligation of perfect duties. Thus Mill suggests that the line between *ought* and *could* is defined by enforceability of the former. Traditionally this enforcement has been linked to an understanding that perfect duties correspond to rights. We have an enforceable duty only if someone has a reciprocal right: for example, a duty of forbearance in respecting someone's right to their private property. But being a utilitarian, Singer does not make use of the language of rights in his argument (for example rights of the starving or badly-off to be helped or saved), although the urgency and rigidness of the duty to avoid bad consequences is strikingly similar to that associated with the trumping of rights.

Thus utilitarianism does not offer the possibility of delineating perfect and imperfect duties via references to rights. How shall our obligations be limited then? Michael A.Slote has suggested a reversed Golden Rule, which he terms Brazen Rule[164], namely:

> "*it is not wrong to omit doing something to others that others would have omitted doing for you, if your positions had been appropriately reversed, as long as doing the thing in question would not seriously interfere with your life plans and those plans do not involve any commissive immoralities.*"

---

[162] Although Kant also discussed the imperfect duty of beneficence, perfect rights and duties were also elaborated by Pufendorf in 17th century. Samuel Pufendorf, *On the duty of man and citizen according to natural law* (Cambridge: Cambridge University Press, 2000): 69.

[163] John Stuart Mill, *Utilitarianism* (New York: Prometheus Books, 1987): 65.

[164] Michael A. Slote, "The Morality of Wealth," in *World Hunger and Moral Obligation*, 139.

Our duties are limited by imaginative reversal of positions, of what we could expect others to do for us. In an interesting way, the important aspect of reciprocity that is often highlighted as the central tenet of any moral system is preserved here. Demands of the principle of beneficence should be dependent upon the compliance of others to the same principle — for example I am required to give the amount that would be required of me in case of full compliance by all[165]. Relevant to benefit-sharing is Slote's admission regarding the immorality of a situation where the continuation of our life plans is dependent on the perpetuation of wrongdoings elsewhere. If our life plans hinge on the exploitation of others, then the argument of non-interference with the life plan is invalid.

The charity/duty distinction has been employed to allow for a discrimination among the many causes to which our attention is needed. By not setting clear limits to his principle Singer in a way "merges all morality in justice"[166]. James Otteson echoes this point in suggesting that Singer has conflated two separate moral conceptions: virtue and justice[167]. Illustrative is Adam Smith's account on differentiating between the two: what is virtuous is as hard to define as the style of a piece of writing whereas rules of justice are grammar-like — few but clear[168]. It is argued that there should be a realm of virtue and vice that is somewhat distinct from that of justice and injustice. Differentiation can lie in enforcement — Mill insisted that we can determine whether an act was unjust by considering the possibility of punishment. If we would agree with punishment, the act should have been an obligation, if not, it belongs to charity and the virtuous. While this approach corresponds better to some of our common sense understandings of morality, there is a problem in insisting that leaving the child to drown in the shallow pool involves no "positive harm" (e.g. I have not thrown the child in myself) and thus no injustice. Inactivity is also a type of activity.

But Singer does not discuss the possibility of punishment in any traditional sense either. There is no strict duty/charity delineation that is defined by the institution of enforcement. Consequentialism can work in cases where everyone voluntarily adheres to the principle of avoiding harm but this does not seem to be the case at least regarding universal benefit-sharing. The Brazen Rule proposed by Slote suffers from the same weakness — an immoral egoist would not expect any help from others and is not willing to give it either; the reciprocity dependent on voluntariness and empathy is very delicate. Sanctioning this rule of avoiding harm would require references to concepts outside utilitarian thinking, for example rights. Additionally, the complicated

---

[165] Murphy, "Demands of Beneficence", 280.

[166] To quote Mill, *Utilitarianism,* 67.

[167] Otteson, "Limits on Our Obligation to Give,"183–203.

[168] Smith, *Theory of Moral Sentiments,* 174–175.

issue of defining (potential) harm that qualifies as the ground for the enforcement of the principle becomes an issue when sanctioning is considered.

Traditionally morality has been restrained by division between charity and justice, thus some of it left dependent upon benevolence, but this does not satisfy Singer's objective of ensuring justice in all morality. But perhaps traditions can change also in morality? Could it be argued that moral norms like the duty to avoid harm can develop from being dependent on benevolence to being increasingly implemented in legal codes and can benefit-sharing be an instance of this process? This might involve the inclusion of moral concerns and principles from outside the consequentialist thinking, although I suppose that "purity" of moral theories is not a big price to pay for the actual engagement with significant concerns. Life never is an exemplary version of any theory and no theory can cover the fullness of living a life.

3.4. Can implies ought?

At least the history of law illustrates that the advancement of societies and civilisations is usually paralleled by the increasing complexity of legal codes and regulations (for example aviation brought along aviation laws etc). Could we speculate on the same process also regarding human morality (that is partly tied up with legal norms anyways)? In some instances there is clearly a progression from charity to duty in both legal and moral norms. For example, issues of welfare and social care were for centuries a central part of charitable activities. Especially in the 20th century Europe this subject matter has increasingly become part of justice and enforceable duties usually taken up by the state have become commonplace. The process has of course been largely paralleled by the improvement of economic circumstances that has allowed for the "taking on" of new duties. This brings me to an interesting issue regarding the relationship between contingencies and morality. Is morality, in a way, a positivist subject matter that the more we can do, the more we should? How much is morality dependent on what we can deduce from the description of empirical facts?

Consequentialism is by definition very much centred on the relevance of empirical data.

There is strong reliance on the arguments that arise from empirical circumstances of a specific situation and are removed from metaphysical presuppositions. For example, as regards universal benefit-sharing requirements, could it be argued that we ought to engage in sharing because we are now in a position to really help and make the difference? There have been inequalities and injustice in the world throughout its history but it can be argued that the inequalities have never been as severe as they are now[169] and the harms we should be preventing are serious and require moral response. If in the past almost everyone was poor, then for example redistribution would not have significantly improved the situation (nor were there sufficient means available for instituting such measures). Nowadays inequalities are grave and redistribution would make sense as the industrialised countries do have the necessary sources to alleviate the situation. Perhaps it can be argued that what were previously supererogatory acts have now descended to a level of common sense morality? Thus does the capability to help create a duty to help?[170] Or to reverse an old saying — does can imply ought?

Jeremy Waldron has asked a somewhat similar question — do circumstances create entitlements[171]? Does the global famine context create entitlements to food? Does the increasing gap in health care services between developing and industrialised countries originate appropriate moral claims and obligations? Waldron discusses property rights in a way that is also relevant in the genetic resources debate. He claims that:

> *"the burden of justifying an exclusive entitlement depends (in part) on the impact of other's interest of being excluded from the resources in question /…/ acquisition which is legitimate in one set of circumstances may not be legitimate in another set of circumstances."*[172]

While he focuses on entitlements and specifically rights discourse, he explains that circumstances can influence principles of morality. For example applying this logic in the sharing of benefits, this would mean that the exclusive property rights in certain genetic products or resources might have to give way to entitlements to those entities by those previously excluded if conditions change. This is a position that recognises that justice and injustice claims should be responsive to circumstances and to changes in circumstances.

How is that change of circumstances influencing the delineation between charity and duty as regards Singerian principle of prevention of harm? Is the consequentialist duty to help context sensitive? For example, what of the possibility that the mere scale and potential impact of genetic research creates a new qualitative argument for benefit-sharing that is based on duty? The possible argument (that is both dependent on circumstances and based on utilitarian logic) could go something like this: in a globalising world, where increasingly

---

[169] See for example Brian Barry, *Theories of Justice*, Vol.1 (Berkeley: University of California Press, 1989): 4–5.

[170] Admittedly, this is a very shaky ground for argumentation — we all have many capabilities, for example also that to kill. However, it is likely that most would not want to derive any duty to do so.

[171] Jeremy Waldron, "Superseding Historic Injustice," *Ethics* 103, 1 (1992): 20.

[172] Ibid., 24.

all humans are linked through various networks of dependence, benefit-sharing would bring about better conditions of living, more access to needed drugs and therapies, to more people. A reformulation of the same position would insist that bad consequences will happen if we do not practice benefit-sharing as globalisation also means global crime and drugs trafficking, environmental destruction, and the global spread of diseases like AIDS and SARS as risk factors and communicable diseases spread[173] etc. Could the global economic, political and other contingencies have caused us to consider benefit-sharing, and especially it becoming a duty instead of charity?

Benefit-sharing, especially as regards biomedical and genetic research, is a complex subject matter where moral principles and empirical factors are both significant in shaping the concerns and the entire debate. One could argue for the principle of preventing harm as the justification for benefit-sharing and this principle itself is not context dependent (we would have a duty to avoid harm in all circumstances). But context dependent is very much what one should specifically do to enforce benefit-sharing and respect the moral duty that we should better the lives of people by avoiding harm. Perhaps it can be argued that within benefit-sharing the context — the actual concerns, difficulties, dangers, possibilities and other contingent factors both prescribe and limit the scope of the duty that consequentialism insists upon. This is possibly a too abstract of a construction but it points to an important nexus of principles and practice. Duty to avoid harm is a very appealing moral rule but it is also a very abstract and demanding one. As a possible justification for benefit-sharing, it cannot stand alone and can therefore be of use alongside other justifications or having to be elaborated to a more specific degree. One possibility would be to recognise that it is a matter of specific circumstances whether the duty is part of justice concerns or belongs to benevolence.

3.5. Avoiding harm in biomedical research — whose responsibility?

In case of global hunger Singer's stress was on the moral requirement that all individuals contribute to the project of avoiding significant harm (by donating money, time, and resources)[174]. Perhaps a parallel from genetic research would be that people should contribute to buying life-saving drugs for those who need them. On the other hand, in the previous chapter I have insisted that at least on the level of universal benefit-sharing (if the availability and accessibility of the

---

[173] Detlef Schwefel, "International Health in Globalised Development Perspective," *Journal of Public Health* 12 (2004): 177–184.

[174] Singer also argues for necessary government action in giving aid but he stresses that individual contributions are still required to ensure that one practices what she preaches. "Famine, Affluence, and Morality", 240.

results of genetic research to the global population is argued for), changes are needed in ways the global economic and political structures function. Individual contributions here are appropriate as well but quite likely not sufficient. Avoiding harm or bringing about utility should also be the duty of the governments and supra-national organisations.

In this context the negative utilitarianism of Singer can be compared with the precautionary principle that has taken hold in environmentalism as well as in various fields of applied ethics in the European context. The principle similarly stresses the prevention of harm as the core of morality and insists that we should not undertake action A, if it is likely to cause B (B considered a very harmful event, condition etc) [175]. Both negative utilitarianism as well as the precautionary principle are focused on risks — potential harms, but in comparison with the utilitarian risk assessment, the precautionary principle is more circumspect. It has been argued that the difference between these two approaches is that of principle and not of degree[176]. Precautionary principle limits an action not as a result of risk assessment but simply because of an uncertainty, a possible threat to something that is very highly valued. When a certain value is in potential danger, precautionary principle does not allow it to be weighed against other concerns.

For instance, a common example from bioethics describes a scenario where various methods of gene technology could institute permanent changes in human genetic setup. If the present human genome is defined as being of very high value, the precautionary principle could sanction the banning of genetic technologies that might threaten this value and lead to undesirable results. The degree of scientific uncertainty as regards the likelihood of these events is not relevant in comparison with the utilitarian calculus. In a way, the precautionary principle limits the application of risk assessment, it attempts to protect certain values that are un-tradeable and not suitable for comparative evaluations.

The responsibility for the implementation of the precautionary principle has mostly been solved through legislation, both national and international. Political institutions in Europe have been urged to take the responsibility of implementing the precautionary principle[177]. Harm prevention, whether based on risk assessment or precautionary rationale, is to be undertaken institutionally. Benefit-sharing can also be constructed as a way of preventing potential threats and hurtful results. Whether it is to be undertaken because it would maximise utility and avoid harm as utilitarians would argue or because it would respect certain undisputable values like human dignity, justice and equality (a

---

[175] Häyry, "Precaution and Solidarity", 199–206.

[176] Ibid., 199–206.

[177] European Commission, *Communication On the Precautionary Principle*, 2000; available from http://europa.eu.int/comm/dgs/health_consumer/library/pub/pub07_en.pdf; accessed 17.08.2005.

precautionary position), the duty to implement needed measures is a political one.

In biomedical research an important actor with significant responsibilities has been the research agency or pharmaceutical industry pursuing research. In this context a duty to avoid harm has been most clearly expressed through the duty to avoid exploitation — a principle that has a prominent presence in many guidelines and regulations overseeing biomedical research[178]. I have borrowed a definition from Ruth Macklin:

> *Exploitation occurs when wealthy or powerful individuals or agencies take advantage of the poverty, powerlessness or dependency of other by using the latter to serve their own ends without adequate compensating benefits for the less powerful or disadvantaged individuals or groups*[179].

This is but one possible definition among many but contains an important recognition that exploitation involves harm and that it is very much linked to the power inequalities. Similar attention to the issues of power is present in cases where the duty not to exploit is expressed by stressing the immorality of taking advantage of the vulnerable.

In biomedical research the duty to avoid harm has been mostly a responsibility of the agencies undertaking research. Increasingly this moral principle is enforced by the international and national overseeing and regulatory bodies, academic publications and of course, funding organisations.[180] UK Nuffield Council report on research in developing countries underlines the duty to avoid exploitation as one of the most important moral concerns guiding research. This is the duty of both organisations as well as individuals and it is based on the *"principle of respect for persons, for in exploiting others we fail to give proper weight to their interests*"[181]. In addition to sponsors and researchers it is also the duty of governments to take care of their populations, to protect them from harm.

---

[178] For example Nuffield Council, *The Ethics of Research Related to Healthcare in Developing Countries*; NBAC, *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*; CIOMS, *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, esp. guideline no 10.

[179] Macklin, *Double Standards*, 101–102.

[180] European Commission, *Directive on Clinical Trials 2001/20/EC*, 2001; available from http://eudract.emea.eu.int/docs/Dir2001-20_en.pdf; accessed 12.08.2005.

[181] Nuffield Council, *The Ethics of Research Related to Healthcare in Developing Countries*, 52.

3.6. Conclusion

This chapter has focused on analysing a consequentialist moral principle, specifically the negative consequentialist argument developed by Peter Singer, as a possible justification for benefit-sharing. The duty to avoid harm is intuitively appealing and certainly morally laudable. On the other hand, the Singerian principle suffers from being too demanding. People have always had duties towards others but these duties have been limited and there has been room for so-called voluntary duties or benevolence, a part of morality that seems to be somewhat missing from this specific consequentialist account. I have suggested that if to be applied within benefit-sharing, this principle needs to be limited.

Traditionally this has been achieved through the charity/duty delineation and by the inclusion of the concept of rights. This however changes the argument already by defining the avoidance of harms through respect towards rights (harm equals violation of rights). One possibility for elaboration and specification of the consequentialist duty to avoid harm in the benefit-sharing context could well lie in the inclusion of empirical data: for example prioritising among harms could be based on what sorts of harms are currently prevalent or are being foreseen as potentially serious in the future.

If the consequentialist duty to avoid harm is to stand as a justification for benefit-sharing, it needs to elaborate on the specific types of harms to be avoided. Exploitation is one possible and also more graspable concept that limits the otherwise very demanding consequentialist principle of avoiding harm. Instances of exploitation might also be easier to pin down than deciding on the nondescript concept of harm.

CHAPTER 4. ARGUMENT THROUGH RIGHTS

4.1. Introduction

Rights are one of the most central concepts in political philosophy regardless of one's ideological inclinations. Whether hailed as the sole protector of men against the injustice of others or denounced for constituting the individual as the only relevant and fundamental category, rights are important. Although I will be focusing on rights for such a large part of this work, I do not intend to suggest that rights exhaust morality. But they do have a special status and in the realms of politics they have special weight.

How shall I argue for the relevance of rights discourse in benefit-sharing? While the rights-language is widely employed in a number of international documents, application of rights in benefit-sharing is much rarer. One of the exceptions is the United Nations International Convention on Economic, Social and Cultural Rights that recognised "*the right of everyone to enjoy the benefits of scientific progress and its applications"*[182]. Universal Declaration on the Human Genome and Human Rights insists that "*benefits shall be made available /…/ with regard to/…/ human rights*"[183]. The HUGO Statement subscribes to the adherence of international norms of human rights[184]. While declaring respect for rights is surely laudable and necessary, the actual employment of rights in benefit-sharing should be investigated.

For example, research on non-human biological resources has made active use of the property-right argument. The subject matter of human genetic material as property has been much discussed but inconclusively so. The first infamous legal case in establishing a property right in one's bodily material concluded that even if one would own the specific cells in one's body, this did not mean that also the cell lines derived from it would be owned[185]. The owner(s) of the genetic data have not done anything to make their property valuable and therefore, at least in terms of patenting, should not have similar rights as researchers who have added value to it[186] — a sort of Lockean understanding of mixing one's labour with natural resources[187]. David Townend

---

[182] United Nations, *International Covenant on Economic, Social and Cultural Rights*.

[183] United Nations**,** *Universal Declaration on the Human Genome and Human Rights*

[184] HUGO, *Statement on Benefit-Sharing*.

[185] On *Moore v. Regents of University of California* see Charles A. Erin, "Who Owns Mo? Using historical entitlement theory to decide the ownership of human derived cell lines," in *Ethics and Biotechnology*, ed. A. Dyson and J. Harris (London, Routledge, 1994): 157–178.

[186] Chadwick, Berg, "Solidarity and equity", 320.

[187] Locke of course had an important clause to the property-creation process, namely this was only allowed when "there was still enough and as good left". It is questionable whether patenting gene functions and sequences does leave enough for others. John

has concluded that the only function that the property right in one's own genetic information can have, is that of a shield[188]. That is, property right in this case allows for protection only, and not for exploitation, selling or buying.

It is also possible to conceptualise the human genome as common property. UNESCO declaration on the Human Genome and Human Rights establishes genome as a heritage of humanity in a *symbolic sense* and also insists that *"the human genome in its natural state shall not give rise to financial gains"*. At the same time such wording is not capable of supporting legal action and in reality, the abovementioned declaration, as well as others that stress the need for benefit-sharing, (e.g. the HUGO Statement on the Principled Conduct of Genetic Research), exist side by side with others that directly contradict these ideals and principles (like the WTO's Trade Related Aspects of International Property Rights, the TRIPs agreement)[189]. Concept of genes as common property would be able to provide symbolic support for benefit-sharing in pointing to our shared humanity in its biological expression but I suggest that this would constitute an additional ideological argument for global solidarity and not resemble an interaction based on property right.

While the issue of property rights in human genetics is a fascinating topic, I will not pursue it here but will instead focus on another possible rights-based argument, namely on the right to health care. But I do not claim that this exhausts the rights discourse for the purposes of benefit-sharing although I do think that at present the right to health care provides an important rationale for benefit-sharing. If universal benefit-sharing is to be employed outside of biomedicine (e.g. in access to information technologies) then other rights would perhaps be more appropriate. But a right to health care could successfully provide a basis for benefit-sharing, especially in its medicine-related domains.

I propose that the right to health care has special relevance in benefit-sharing because overwhelmingly the results of research and development activities in human genetics pertain to human health and well-being. And while genetics will surely contribute to other areas, applications in medicine have so far been predominant and their importance is a long-term one. The aim of benefit-sharing especially within human biomedical research is to ensure that the developments and products of this research are accessible to those who might need them in order to live a life that is free(er) of diseases and pain, that allows the person to exercise choice and live according to her version of the good life.

Locke, "Second Treatise on Government," in *Two Treatises of Government*, ed. P. Laslett (Cambridge: Cambridge University Press, 1996): 286–291(5, 26 & 33).

[188] David Townend, "Who owns genetic information?" in *Society and Genetic Information, Codes and Laws in the Genetic Era*, ed. J. Sandor (Budapest: Central European University Press, 2003): 142.

[189] UNESCO Declaration on the Human Genome and Human Rights; HUGO ELSI-Committee, *Statement on the Principled Conduct of Genetic Research*, 1995; available from http://www.gene.ucl.ac.uk/hugo/conduct.htm; accessed 15.08.2005

As I will argue below, much of the reasoning behind concepts like rights (and especially that of the right to health care) points to the very same purposes.

Last but not least, rights are also the most policy-friendly justificatory basis for benefit-sharing. While calls for solidarity and the principle of avoiding harm are serious instruments in moral philosophy and on the level of rhetoric, it is much more difficult to actually implement these notions from a governance point of view. Therefore establishing rights language in benefit-sharing would be an important step in moving towards the factual fulfilment of benefit-sharing goals.

I will start out with a short introduction into the taxonomy of rights and continue with the historical overview and an emphasis on the “rights of man” and the later human rights. Subsequently, I will concentrate in more detail on the question of negative and positive rights, attempting to justify the latter against some important lines of criticism arising from libertarian philosophy. Once a possibility of positive right is philosophically justified, I will focus on two particular accounts that argue for a right to health care — those of Norman Daniels and the Amartya Sen-Martha Nussbaum capabilities/functionings account. Towards the end of the chapter I will return to the assessment of rights-language in benefit-sharing and examine the issue of responsibilities in this context.

4.1.1. Classification

Rights are important for many reasons. They allow us to pursue our own goals and provide us with self-assurance and respect when we need to insist on some actions from others. They are indeed like “moral furniture”[190] — enabling us to stand on the table if needed or providing us with the comfort to lounge around. Traditionally in philosophy rights-based approach is contrasted with consequentialist reasoning, mainly because consequentialist calculations would allow for the violation of rights for the purpose of achieving some common good. It has been argued famously that rights are like trump-cards that enable us to guard our privacy in the face of utilitarian thinking that would otherwise remove certain decisions from our personal discretion in the name of maximising the common outcome[191]. Furthermore, rights are important also because they establish a zone that remains outside rights discourse, allowing for the exercising of benevolence, supererogatory acts, for the releasing of rights and surrendering of one’s claims[192]. They provide morality with the potential of

---

[190] Joel Feinberg, *Rights, Justice, and the Bounds of Liberty* (New Jersey: Princeton University Press, 1980): 151.

[191] Ronald Dworkin, “Rights as Trumps,” in *Theories of Rights,* ed. J. Waldron (New York: Oxford University Press, 1995): 153–167.

[192] Feinberg, *Rights, Justice, and the Bounds of Liberty,* 156–157.

distinctions that enrich and refine the treatment of this subject matter (e.g. the duty-charity delineation).

The most well-known dissection of the concept of right was introduced by American legal theorist Wesley Newcomb Hohfeld. Although the varying content of the notion of right was recognised much earlier (as he himself points out through many quotes from judicial literature and court opinions), Hohfeld was the first to elaborate the conception systematically[193]. The concept of right can contain several different meanings:

1) Right as a claim. Claim rights are perhaps the most classic type of rights and they have a corresponding duty. For example if I have borrowed money from a friend, I have a duty to repay it and she has the right to receive it. Having this type of right means being in a position to claim something (provided the claim is valid).

2) Right as a privilege or liberty to do something. This type of right can be defined as an absence of a duty[194]- I can choose to do something if I do not have a duty to do it. If there are actions that I have to do (duty) and should not do (duty of non-interference), then the rest of the possibilities open to me fit under liberty. It is also possible to define privilege in a more restricted manner than mere liberty, for example in a sense that liberties can be more widely distributed in the society than privileges (thus latter as a special kind of liberty).

3) Thirdly, right can be a power. This includes the power to create a right or transfer a right. For example because I have a right to my bicycle, I also have the power to transfer this right to my friend, who will consequently have the right to the bicycle.

4) Fourthly right can be an immunity. Having a right as immunity protects me from consequences of actions that would infringe on my rights. For example my right to vote is immune to my neighbour's decision to annul my right to vote.

Many rights cannot be identified solely with one Hohfeldian category. Certainly what are known as human rights are complex assemblages of several qualities and this is true in case of many other rights as well. A distinction between two classes of rights is useful. In what follows, I will focus on rights (human rights) that people have because of their status as humans. But of course there are also plenty of rights that are a result of our agreements, relationships, voluntary actions and simply law.

What is the relationship between moral rights, legal rights and human rights? Legal right is easier to pin down as it is usually available in an accepted written form (although there still remain the shadier penumbral issues). Ideally legal human rights should be backed by moral rights, meaning moral rights should be prior to those legal rights but there remain moral rights that are not written into

---

[193] Wesley Newcomb Hohfeld, *Fundamental Legal Conceptions* (New Haven: Yale University Press, 1923).

[194] Joel Feinberg, *Social Philosophy* (New Jersey: Prentice Hall, 1973): 56.

law. Moral rights are not a clearly definable assemblage, nor are they coherent as various theories do not agree on the content of moral rights. Therefore legal human rights are sometimes a compromise between various versions of moral rights. Furthermore, the exact role, significance and scope of rights in morality as such is an important subject matter that cannot be explored here in depth[195]. My focus will be on human rights that are moral rights and the assumption is that valid and important moral claims can be expected to be established as legal rights[196].

Some theories insist on the perfect correlation of rights and duties although this is one of those issues where philosophers have disagreed over time and probably continue to do so as a position on this question has sensitive moral and political implications. A classic liberal approach and a more contemporary libertarian one would insist on the perfect correlation of rights and duties (and therefore my duties can only be created through someone's correlating rights). Alternative argument would allow for the separate existence of these two notions and I propose to argue the same. McCloskey has insisted that rights are really our entitlements "to do, have, enjoy or have done" and cannot be identified with specific duties, as the means of satisfying our entitlement will depend on the circumstances[197]. Therefore the content of duties cannot be identified beforehand as the strict correlation of rights and duties would require. This is similar to what Joseph Raz argues, namely that the correlative approach disregards the "dynamic aspect of rights"[198]. An existence of a right is only a ground for a duty; duty itself will depend on the circumstances.

I will assume that few examples on non-correlating rights and duties[199] will be enough to prove this point. Based on Hohfeld's taxonomy it follows that

---

[195] For a sketch of rights-based morality see J. L. Mackie who argues that any acceptable moral theory must be rights-based (which does not mean that rights are the only elements of morality). "Can There be a Right-Based Moral Theory?" in *Theories of Rights*, ed. J. Waldron (New York: Oxford University Press, 1995): 168–181. On the opposite view see Joseph Raz, *The Morality of Freedom* (Oxford: Clarendon, 1988): 193–216 (chapter 8 "Right-Based Moralities").

[196] This assumption is not shared by everyone. For example Thomas Pogge insists that the conceptual connection between human and legal right should be avoided. This is necessary so as to allow for alternative ways of establishing rights in diverse cultural and economic contexts. *World Poverty and Human Rights,* 46.

[197] H. J. McCloskey, "Rights," *Philosophical Quarterly* 15 (1965): 115–127.

[198] Raz, *The Morality of Freedom*, 165–192.

[199] Feinberg sometimes differentiates between correlation and correlativity on this issue. The first is a proposition that acceptance of duties is a prerequisite for having rights. For example Gandhi has argued that one only has a right, when she has fulfilled a duty — "deriving every right from a prior duty". Although this reciprocity might be an agreeable position, it is by no means a logical one. Correlativity is an understanding that someone having a right logically requires someone having a duty as regards that right. Traditionally moral and political philosophers have focused on the question of

certain rights (claim-rights) obviously require the existence of parallel duties. But there exist both legal and moral duties that do not have a corresponding right. In legal terms one can have a duty to stop before the traffic sign although there are no other cars or pedestrians in sight — this is a legal duty of obedience with no *prima facie* rights-bearer[200] corresponding to that right. One can also think of a right without a corresponding duty — e.g. your right to marry does not entail someone's duty to marry you (this is an example of a right as immunity — no-one can deny you the right to marry). What kind of right can be an applicable tool in universal benefit-sharing? *Prima facie* it seems that the employment of rights would entail mostly claim rights. It is then a question whether to argue for this right within the traditional liberal framework of strict right-duty correlation, or would it be preferable to insist on this right as entitlement?

In personam right is a right that one has against a specific person either in positive terms (to carry out a duty) or negative terms (forbearance). In case of *in rem* rights the person with a specific duty that corresponds to one's right cannot be designated (at least beforehand). *In rem* rights are rights against the whole world, so to speak. For example my right in my land property is *in rem*, as the entire population of the world has the *prima facie* duty to refrain from trespassing. Positive *in rem* right is a claim that can be recognised and acknowledged without prior duty-relegation. Thus the claim would give rise to a duty of need-fulfilment, a duty that "abundance owes to need."[201] There is also a possibility for a right in "manifesto sense"[202]. This would be a claim against the world which does not (yet) have direct correlations in someone's duties.

The following short excursion through the history of rights discourse will serve to give some background to a more detailed investigation of this issue in the later section.

4.1.2. Human rights

How are human rights generally characterised? Firstly human right is a right that belongs to all humans, universally. Thus it is a very powerful, demanding and certainly a pretentious right, a universally applied and necessarily valid

---

correlativity in Feinberg's sense. Mahatma Gandhi, *Moral and Political Writings,* ed. R. Iyer, Vol. 1 (Oxford: Clarendon, 1986): 497. Feinberg, *Social Philosophy,* 61–64.

[200] The expression "*prima facie* rights" is sometimes criticised as it seems to allow for the possibility that in case of overriding or infringing rights, there had actually been no rights involved at all. But this does not necessarily follow and I will stick to it, as it is a straightforward expression to acknowledge the non-absoluteness of these rights.

[201] Feinberg, *Rights, Justice, and the Bounds of Liberty,* 133.

[202] Joel Feinberg, "The Nature and Value of Rights," *The Journal of Value Inquiry* 4, 4 (1970): 255.

moral claim. Human rights are acquired by the mere fact of being human, they are not based on nor dependent upon agreements. Human rights cannot be transferred, or given up or bought, they are inalienable. Perhaps it is useful to focus shortly on a historical overview that abounds with lively debates on the validity and effectiveness of these moral rights.

Where do rights come from or what is the basis for rights? Leaving aside the proposition that rights are of divine origin, two major approaches can be distinguished: rights as arising from (human) nature and rights as a result of positive law.

Most commonly human rights are seen as evolving from a tradition of natural law and rights. Aristotle thought that purpose-driven nature and the law within it was the original blueprint for legal and moral law and had to be followed in human affairs — a first expression of a concept of natural law[203]. Through later contributors, like William of Ockham who is credited with coining the notion of natural right[204], and John Locke's influential analysis on the trinity of natural rights (to life, liberty and property) [205], human rights have been based on the universal commonality of human nature. So despite the fact that "rights of man" became human rights only in the 20th century, the philosophical tradition is a long-standing one.

One of the main reasons for the philosophical and political attractiveness of natural rights derives from their critical potential in disregarding the established social conventions and regulations. But this very same detachment from descriptivity presents also the most problematic aspect of this approach, namely the epistemological challenge: how can we learn of a natural law and the rights within it? Margaret MacDonald has summed up the problematic side of natural law and rights in a following quote:

> *"It seems a strange law which is unwritten, has never been enacted, and may be unobserved without penalty, and peculiar rights which are possessed antecedently to all specific claims within an organised society."*[206]

---

[203] Aristotle, *Politics*, ed. by S. Everson, transl. by B. Jowett (Cambridge: Cambridge University Press 2000), book I, 2.

[204] William of Ockham, *The Work Of Ninety Days,* trans. and ed. John Kilcullen and John Scott (Lewiston: Edwin Mellen Press, 2001).

[205] Locke, *Second Treatise of Government.*

[206] Margaret MacDonald, "Natural Rights," in *Theories of Rights*, ed. J. Waldron (New York: Oxford University Press,): 22.

Indeed, Jeremy Bentham argued forcefully that referring to supposedly existing natural rights is “nonsense upon stilts” that is bound to lead to chaos[207]. Instead men should focus on legal rights that are to be justified through the consequentialist reasoning of common good.

Natural law cannot be studied by observation or deduced from experience but its basis lies in the shared nature of men, for example in the existence of the faculty of reason. It is by reason that we can argue for the ideal from the mundane and it is also reason that supposedly differentiates us from other living creatures[208]. We are able to reason about human goals, needs and interests and thus argue for a basis for rights (as means for furthering or fulfilling these needs and interests).

But rationality is certainly not the only possible foundation for natural law. Both Hobbes and Locke assert that natural rights arise from the human need for self-preservation and as this need is shared by all, it also forms basis for equality of natural rights[209]. Legal philosopher H.L.A.Hart centered on a single natural right — the right of all men to be free — as the basis for all other rights in his earlier work[210] but later outlined several starting-points for natural law in his *The Concept of Law* (human vulnerability, limited altruism, limited resources and limited understanding and strength of will)[211]. All of these propositions can in principle be criticised, especially by stressing the fact that most of these qualities are bestowed on humans in different degrees thus subverting the premise of being shared in more or less comparable ways.

If an acceptable basis for natural rights cannot be agreed on and the unanswered epistemological issues make it necessary to rule out the natural law-based approach to rights then it is always possible to turn to positive law

---

[207] Jeremy Bentham, *Rights, Representation, and Reform — Nonsense upon Stilts and Other Writings on the French Revolution,* eds. Philip Schofield, Catherine Pease-Watkin and Cyprian Blamires (Oxford: Clarendon Press, 2002).

[208] Reason, of course, is not a simple graspable category. Especially in bioethics literature the concept of shared rationality as a basis for rights has been challenged with the examples of newborns and severely mentally ill people. Despite their lack of rationality, we would still want to accord to them the protection and dignity that for example right-based approach would provide. Leaving aside the Singerian accusation of speciesm, I would like to suggest that reason and rationality do provide one with (an admittedly vague) conceptual tool for analysing these important philosophical issues at certain theoretical level. See for example Michael Tooley. “Abortion and Infanticide,” *Philosophy & Public Affairs* 2,1 (1972): 37–65; Singer, “Taking Life: The Embryo and the Fetus,” in *Practical Ethics*, 135–174.

[209] Hobbes, *Leviathan,* 238–239; John Locke, *Two Treatises of Government*, 271 (II, 5).

[210] H. L. A. Hart, “Are There Any Natural Rights?” in *Theories of Rights.*

[211] H. L . A. Hart, *The Concept of Law* (Oxford: Clarendon Press, 1961): 189–195. See Bryan Turner for a sociological attempt to ground human rights in human frailty/ vulnerability of the body, social precariousness and moral sympathy. Turner, “Outline of a Theory of Human Rights,” *Sociology* 27, 3 (1993): 489–512.

and insist that rights are just decisions that humans have made. This robs the discourse of its somewhat high-flown normative pretensions but does establish rights nevertheless. Within this tradition rights are seen as man-made, not handed down by God or arising from human nature but essentially a decision by humans about humans. Accordingly rights, including human rights, are whatever we decide they are, leaving the content of those concepts up to various agreements and procedures. This line of thought can take several forms, from the contractual, still rationality-based law-making to a very practical approach geared towards educating and conditioning people to adhere to rights voluntarily[212]. The problem with these positive and pragmatic approaches is the accompanying relativism that is often deemed unacceptable for a concept that normatively aims at achieving universality. I will look into the problem of relativism in a later section of the work but would just like to note at this point that proponents of positive law might very well live with an understanding that human rights universalism might be unenforceable and should not be expected.

Traditionally, the history of human rights or "rights of man" has been divided into three generations. The first generation, sometimes identified as liberty rights, includes political and civil rights. Although influentially explained by Locke during the seventeenth century as the rights to life, liberty and property, this line of thought links back to the drafting of the English Magna Carta in 1215 and culminates in the American Declaration of Independence (1776) and the French Declaration of the Rights of Man and of the Citizen (1789). In some political traditions (like libertarianism) these rights are still considered the only justified rights and in others they are often accepted as fundamental rights from where other human rights can be derived from.

The second generation rights, or equality rights, include social, cultural and economic rights. The majority of these rights were internationally acknowledged and established with the UN Universal Declaration of Human Rights in 1948. Of the thirty articles in the declaration, the last eight outline second generation rights like the right to work and leisure, the right to an adequate standard of living in terms of health care and other social services, the right to education and so forth. The acceptance of second generation rights is based on an understanding that civil and political rights of the first generation are not sufficient for human welfare and flourishing. As the quality of human life is dependent upon the social structures that can be of great hindrance, human well-being cannot be satisfactorily achieved only via first generation rights.

---

[212] For example, Richard Rorty is convinced that sentimental education is a key to the advancement and protection of human rights. We would just have to accept the fact that TV programs on war atrocities are capable of doing more than any abstract insistence on human rights ever will in terms of protecting actual people. Richard Rorty, "On Human Rights, Rationality and Sentimentality," in *On Human Rights. The Oxford Amnesty Lectures 1993*, eds. Stephen Shute, Susan Hurley (New York: Basic Books, 1993): 111–134.

The third generation of rights called solidarity rights are still in the process of being justified, elaborated and institutionalised. Solidarity rights apply to groups of people, they are collective claims toward other individuals, states and international organisations[213]. Third generation rights recognise the communitarian idea that certain important aspects of our lives cannot be secured via individual-based rights discourse. Accordingly communal values should be recognised as an essential component of any individual life and sometimes group rights can be an effective and justified way to protect these shared interests.

From a traditional liberal perspective the acknowledgement of collective rights poses a potential of conflict with individual rights. It is claimed that human rights cannot belong to only some humans and groups by very definition. But collective rights can allow for the exclusion of certain individual rights in a rather discriminatory way (e.g. limits on the voting of the non-Indian population in Indian territories in Canada). Conflicts of rights are of course commonplace among individual rights themselves but the liberal outlook on third generation rights would usually favour the rights of individuals over groups[214]. One possibility is to not pose the question in terms of either/or but rather in terms of balance as a more inclusive view on the welfare and flourishing of persons might recognise the importance of belonging and communal relations to a good life.

All three generations of rights can be based on some form of understanding regarding the nature of human being in terms of her needs and capabilities. But whereas the first liberty rights are minimal, based on a perception of what kind of creatures humans are; the latter rights decidedly strive towards a fulfilment of what a person can be and allow for the capabilities to grow and flourish. One way of seeing the development of rights discourse is thus as an evolutionary process of moral progress[215]. Human rights that include second generation rights can be seen as opening up a potential for humans to be all that they can be, recognising the pliable side of humans and being determined to support the development towards higher, ideal goals.

---

[213] While not exactly synonyms, the following concepts also belong within collective rights: minority rights, group rights, aboriginal rights, minority protection, special status rights.

[214] For an embracing liberal perspective on these third generation rights see Will Kymlicka, *Liberalism, Community and Culture* (Oxford: Clarendon Press, 1989).

[215] A good example of this account is T. H. Marshall's *Citizenship and Social Class*. Although his focus is on citizenship rights rather than on human rights in general, the same logic of moral advancement is characteristic of many accounts of the latter case.

4.2. Negative and positive rights

The rise of social and economic rights both in practice and rhetoric in the 20th century has been accompanied by passionate discussions in philosophy on the question of whether and how can positive rights be justified. A positive right would insist upon others taking up an activity, of doing something towards a right-owner. A negative right, on the other hand, would correspond to a duty of non-interference from others. There are negative and positive *in rem* and *in personam* rights. For example a positive *in rem* right is acknowledged in some countries in case of accidents where a person in dire need can have a right towards everyone who is in a position to help[216].

In this work I use terms positive and negative right in the abovementioned sense. But this is not the only way to categorise them. As this division has been a subject of heated debates in political philosophy a lot of pages have been devoted to both delineating and oppositely, blurring the boundaries between the two types. For example it is possible to use the term positive to describe rights that are written into law or that are simply deemed enforceable[217].

The classical liberal tradition has mostly insisted on limiting rights to their negative interpretation: me having a right should place a duty to refrain on others. Various explanations have been offered to justify this limit and below I have divided these into three categories. First are the so-called historical baggage arguments. These are expressed not so much by philosophers but are more often visible in political rhetoric. Secondly, there are pragmatic, effectiveness-based arguments for limiting the role of state and thus excluding positive rights. And thirdly, there are arguments claiming that positive rights cannot be justified in moral terms. My counterarguments against these objections to positive rights will follow after each has been introduced.

Historical baggage arguments centre on the descriptive fact that the first generation rights are somehow classic, fundamental, and implicitly insist that "new" rights cannot be introduced for example because they would limit these basic rights. But the fact of limiting rights is not something that is peculiar to positive rights. By accepting in principle that our rights are limited (for example my right to liberty is restricted by your right to life), no qualitative change occurs when positive rights are introduced[218]. As the classic rights to life, liberty and property limit each other, the fact that for example social rights also limit

---

[216] Feinberg calls these positive *in rem* rights also rights of community membership, as the acceptance and fulfilment of such rights is essential for the formation and continuation of a community. Feinberg, *Rights, Justice, and the Bounds of Liberty*, 135.

[217] Maurice Cranston, "Human Rights, Real and Supposed," in *Political Theory and the Rights of Man,* ed. D. D. Raphael (London: MacMillan, 1967): 54–68.

[218] Anthony Honoré, "Property, Title and Redistribution," in *Applied Social and Political Philosophy*, ed. E. Smith, H. G. Blocker (Englewood Cliffs: Prentice-Hall, 1994).

our other rights, is not a fundamental change (of introducing this notion of constraints). It should be explained why only these three rights are in a position to restrain. Additionally the fact that "classic" rights have been established longest in legal terms does not mean that they are inherently more justified than other rights (nor is there a "first come, first served" rule in philosophy). Arguments for positive rights from natural law tradition assert for example that the latter have always existed as moral rights but simply been unsuccessfully realised. Or that positive rights are ultimately derived from negative rights and their fulfilment is necessary in order to fully respect even the classic ones.

Pragmatic arguments against positive rights are linked to a (pessimistic) view that negative rights are a maximum that societies are able to provide for and regulate. It is argued that we are simply not capable of guaranteeing positive rights and by creating rights that go unprotected (like the human right of all to a paid holiday[219]), the status of a right as a moral "must" degenerates into wishful dreaming. Therefore the so-called proliferation of rights (as the appearance of numerous positive rights has been described) will result in devaluing of all rights[220]. From this point of view the realm of rights should not be tampered with (for example, by attempting to coin new rights) as the dressing up of interests in the garb of rights will unavoidably deflate the notion of rights. But the argument of less than perfect enforcement is not a good argument for aborting an otherwise justified process. It is a commonly acknowledged fact that many moral and legal rules are violated regularly but this does not lessen the validity or moral force of these rules.

Positive rights are also seen as requiring massive enforcement and simply cost too much. However, the insistence on the high economic price of positive rights implies that negative rights come free of charge whereas the examples of police forces and the judiciary system testify differently. The latter are institutions with limited resources similar to those servicing positive rights, like the education or health care system. Even private liberty in the classical sense (enforcing the rights to life, liberty and property) depends very much on the existence of these public institutions[221]. Therefore there can at most be a difference in degree and not a difference in kind between negative and positive rights.

Perhaps the strongest arguments against positive rights have been forwarded by Robert Nozick who asserts that, if implemented, positive rights would be immoral[222]. He represents libertarianism — a political theory that limits itself

---

[219] Universal Declaration of Human Rights Article 24 states: "Everyone has a right to rest and leisure, including /…/ periodic holidays with pay").

[220] Carl Wellman, *The Proliferation of Rights. Moral Progress or Empty Rhetoric?* (Boulder: Westview Press, 1999).

[221] For an eloquent case deconstructing this rather arbitrary "cost-based" delineation between negative and positive rights see for example Stephen Holmes, Cass R.Sunstein, *The Cost of Rights: Why Liberty Depends on Taxes* (New York: Norton, 1999).

[222] Nozick, *Anarchy, State and Utopia*.

largely to the question of the role of the state, its starting point being a recognition that there exist certain natural rights. Namely three of them — the right to life, the right to liberty and the right to property[223]. Ones' liberty is limited by rights of others to the same set of rights, thus creating the only political obligation — not to violate the rights of others (basically a duty of forbearance). All rights are negative and in Nozick's version are grounded in Kant's second categorical imperative that states the prohibition of human instrumentalisation: *"Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only"*[224]. Nozick ascertains that this moral rule implies that people have certain rights that rule out the possibility of them being used as (re)sources and thus means for other people. What does it mean to be used as resource/means or being instrumentalised in Nozickean sense?

For that purpose it is necessary to introduce the Lockean argument on ownership.

Nozick starts from a Lockean premise that humans own the fruits of their labour, "they have property in their own person". More specifically they own the fruits of the labour of their body and mind (like abilities and talents). This means that I own the hare that I have caught with my hands or tools, the vegetables that I have grown through my own labour and consequently the money that I might receive when selling those goods[225].

Taxation, as seen from within this framework, constitutes the violation of the rights that one has to her property. Seizing some of my property will diminish my liberty as I will have to involuntarily work for others part of my time (e.g. taxation implies forced labour). Thus the practice of taxing for the purpose of providing welfare rights violates basic rights like the right to property and also violates the dignity and autonomy of a person. This is because taxation is not only an appropriation of property but in a sense a far graver offence of appropriation of people[226], and consequently their instrumentalisation, taking us back to Kant's categorical imperative.

In elaborating on rights as necessarily negative, Nozick has defined them as moral side-constraints[227]. From that position, rights should not be seen as benefits bestowed upon us but rather as limits to actions. In this way rights discourse does not prescribe us our goals but rather functions as a constraint

---

[223] In some interpretations the first two can also be defined as deducible from an essential right of self-ownership, thus making the right to property the only valid natural right. See Jan Narveson, *The Libertarian Idea* (Philadelphia: Temple University Press, 1988).

[224] Kant, "Groundwork".

[225] This all provided that I don't catch a hare that is already owned by someone or grow vegetables on your land without your permission.

[226] Nozick, *Anarchy, State and Utopia,* 172.

[227] Ibid., 28–33.

allowing for the larger liberty in choosing our ends while forcing us to respect certain basic rights through forbearance. Rights as side-constraints are necessary for showing humans the respect they deserve and ensuring that they are not used as means.

To conclude, the moral basis of Nozick's theory resides in two basic tenets: the Kantian prohibition to use people merely as means and the Lockean understanding of self-ownership. These positions are developed into a minimal set of rights that act as side-constraints to people's behaviour. It should be noted that by no means does Nozick insist that these elements exhaust morality but they are certainly the only ones that can justifiably be enforced by the state.

How can this moral case against positive rights be refuted? Firstly, it is hopefully possible to conclude from the above account that Nozick considers rights to be absolute, their infringement being not justified under any circumstances[228]. The question of whether there are any absolute rights and what might these be, is again an important and expansive one in philosophy to which I presently cannot delve into sufficiently. To comment shortly, absolute rights are rights that cannot ever be justifiably infringed. Many philosophers tend to agree that there are no absolute rights[229]. In most cases this is linked to consequentialist reasoning in extreme cases where greater harms can be brought about if a certain right is not overridden. But the very same dilemma might also trigger one to search for some sort of limit as to what can be done to person's rights under these difficult circumstances. Thus libertarians are certainly not alone in proposing absolute rights. Alan Gewirth has offered a "right not to be made the intended victim of a homicidal project"[230]. Joel Feinberg has offered a right to a fair trial, a right not to be tortured, and a right not to be subjected to exploitation or degradation as candidates for absolute rights category[231].

While these candidates for absolute rights mostly have to do with protecting life and liberty, then in arguing for positive, welfare rights, it is necessary to overcome the serious arguments that libertarians have articulated in safeguarding an absolute right to property. One way of doing this is to insist that property rights are only *prima facie* rights and their absoluteness is dependent on the stakes that the owner has in them. Judith Jarvis Thomson proposes that

---

[228] Although there is a famous footnote on p. 30 in *Anarchy, State, and Utopia* where Nozick remarks that: "The question of whether these side constraints are absolute, or whether they may be violated in order to avoid catastrophic moral horror, and if the latter, what the resulting structure might look like, is one I hope largely to avoid."

[229] Gregory Vlastos certainly agrees with that but he also asks how can these exceptions to rights be justified, what are they based on? He argues that the only moral reasons for exceptions are the same moral reasons that are actually behind upholding the very rights they are to provide exceptions for. Vlastos, "Justice and Equality," in *Theories of Rights*, ed. J. Waldron (New York: Oxford University Press, 1995): 48–49.

[230] Alan Gewirth, "Are there any absolute rights?" ed. J. Waldron (New York: Oxford University Press, 1995): 91–109.

[231] Feinberg, *Social Philosophy,* 79–83.

A's right to her property x varies with the degree of which she values it[232]. This makes the stringency or level of absoluteness dependent on the value that the rightholder places on her property. The more valuable the property is, the stricter is the duty of others to respect her property right. This might seem like an unacceptable argument, applying thinking "in degrees" to a concept that has its very essence in avoiding this. But Thomson digs further and argues for the flexibility of property rights from the foundations of rights[233]. In other words, she does not take rights as somehow naturally given but queries for the sources of rights and finds these in human interests. As human interest in not being killed is highly stringent, it might be possible to accord this right absoluteness. In comparison, an interest in some fairly mundane property (like my old pair of shoes) can logically be weaker and thus allow for the needed flexibility in property rights. This idea could be used to justify taxation and redistribution as human interests are tightly linked to human needs[234].

Second possible argument for positive rights also takes a starting point in sources of rights. In discussing what is the basis for side-constraints Nozick briefly elaborates that the reason has to do with certain characteristics that persons have. Leaving aside the traditional concepts like rationality, existence of free will, moral agency and others, he proposes the notion of meaning of life. More specifically: "*A person's shaping his life in accordance with some overall plan is his way of giving meaning to his life; only a being with the capacity to so shape his life can have or strive for meaningful life."*[235] It is therefore for this purpose and from this position that Nozick has argued for a limited set of negative rights as the proper and justified way for allowing for "meaning of life".

Samuel Scheffler has taken precisely the same starting point but argues for a rather different set of rights justifiably arising from it[236]. Namely, if a capacity to live a meaningful life is really the basis from which rights arise (and Nozick himself argues this), then this would require much more than the Nozickean

---

[232] Judith Jarvis Thomson, "Some Ruminations on Rights," in *Reading Nozick. Essays on 'Anarchy, State, and Utopia',* ed. J. Paul (New Jersey: Rowman and Littlefield, 1981):140–141.

[233] Besides looking into the sources of rights (meaning human interest and needs), another obvious way of deciding whether it is justified to override certain rights involves assessment of consequences.

[234] Using the concept of human need is often like opening a can of worms in philosophy. I will here simply refer to Thomson who says that a person at least can be said to have a need in something without which she will die. The person then has an interest in getting this and we might have a basis for flexing property rights in order to provide her with this and save her life. Thomson, "Some Ruminations", 143.

[235] Nozick, *Anarchy, State and Utopia,* 50.

[236] Samuel Scheffler, "Natural Rights, Equality, and the Minimal State," in *Reading Nozick. Essays on 'Anarchy, State, and Utopia',* ed. J. Paul (New Jersey: Rowman and Littlefield, 1981): 148–168.

life-liberty-property rights are able to provide. Scheffler insists that Nozick argues irrationally:

> "*how can one hold* *<u>both</u>* *that rights are necessary to protect and guarantee the valuable capacity to live a meaningful life,* *<u>and</u>* *that people only have rights to* *<u>some</u>* *of the distributable goods which are necessary in order to have any chance of living meaningful lives.*[237]"

As Scheffler noted, the enemy of an ideal to live a meaningful life is then not taxation but starvation[238].

Nozick in his argumentation relies on a position that draws a clear line between person's freedom to do something (freedom equals absence of coercion) and her ability to do it, essentially separating resources and opportunities from the idea and exercise of liberty. Thus being at liberty to do something is distinct from being able to do it. Whereas the first refers to the non-existence of external barriers, the second is dependent on our capabilities or ability to do something. It is claimed by libertarians that one has necessarily nothing to do with the other and providing people with the abilities/resources/ opportunities to do things is not relevant to liberty. Deficiency of resources is seen as not interfering with freedom and choices — "poverty is not unfreedom'[239]. Liberty can be provided for through various regulations, including rights. But enhancing the personal freedom of individuals in terms of their abilities is not an appropriate duty of the state.

This clear separation of ability and freedom is questionable though — if someone is not able to do Y, then she is also not able to exercise the right to do X to which the ability to do Y is a necessary condition.[240] If liberty is connected to ability and resources then the remarkably different opportunities and resources will influence the degree of liberty. What is essential then, is to recognise that freedom is a "rich positive concept"[241] and it is only worth its idealised status if it actually allows for the exercise of liberty.

Furthermore, Scheffler proposes an alternative conception of rights that can actually function similarly to Nozick's own, for example as side-constraints.

---

[237] Ibid.,159.

[238] Ibid.,160.

[239] Raymond Plant, "Why Social Justice?" in *Social Justice from Hume to Walzer*, eds. D. Boucher and P. Kelly (London: Routledge 1998): 269.

[240] Ibid., 269–275. A following example comes to mind: take a person who is without legs or simply not able to walk. In case of political elections she is only able to exercise her right and liberty to vote when a service is provided where someone comes to her home with the ballots and the voting-box or when she is transported to the voting place.

[241] Christine M. Korsgaard, "Commentary on: G.A.Cohen: Equality of What? On Welfare, Goods and Capablilities," in *The Quality of Life*, eds. M. Nussbaum and A. Sen (Oxford: Clarendon Press,1993): 58.

> *Every person has a natural right to a sufficient share of every distributable good whose enjoyment is a necessary condition of the person’s having a reasonable chance of living a decent and fulfilling life, subject only to the following qualification. No person has a natural right to any good which can only be obtained by preventing someone else from having a reasonable chance of living a decent and fulfilling life.*[242]

This right would serve the possibility of meaningful life better, at the same time it would protect the libertarian negative rights in sufficient scope to allow also the ”victims of taxation” a chance of a fulfilling life. Additionally, this formulation sets limits to the requirements of morality and guards against the utilitarian insistence that we are always to do what we can to decrease suffering in the world even if this might mean devoting our lives to it.

I have above attempted to argue that positive rights are a philosophically feasible project, even if one starts to reason from the libertarian premises. If rights are based on human needs and interests, then these can equally ground negative as well as positive rights. Granted that positive rights are justified in principle or at least there are no sufficient arguments for the strict delineation of positive and negative rights, I will proceed to focus on a one such specific right. The right to health care is an important positive right and if established, has important consequences in the benefit-sharing discussion.

4.3. Argument for a positive right to health care

The previous section concluded that positive rights can in principle be justified and I will now continue to analyse a specific positive right, namely a right to health care[243]. This right has special relevance in benefit-sharing discussion as genetic research is first and foremost engaged with the field of health care. It is also most common to associate benefits with more or less direct results of biomedical research. I will start by looking at examples of various international documents that assert this right. While these declarations acknowledge a right to health care, it is necessary to turn to moral philosophy and medical ethics for a systematic elaboration and justification of this right. My main argument for a right to health care will be grounded in two accounts. Firstly Norman Daniels

---

[242] Scheffler, “Natural Rights,”153.

[243] A note on definitions. I will be using the generic expression *right to health care* throughout. In literature also formulations like the right to a decent minimum of health care, adequate level of care and right to well-being are used. While the first of these I consider to be fairly synonymous with the right to health care for the purposes of the present text, right to well-being is too wide in scope, including positive rights also to other goods and services besides health care.

has argued for such a right based on a theory of justice. His account will then be compared to another influential theoretical approach — the capabilities-functionings account of Amartya Sen and Martha Nussbaum. After introducing the central tenets of these theories, I will assess the criticisms jointly and argue for a unified moral justification for the right to health care based on these two approaches[244].

A right to health care is enshrined in a number of international documents. UN Declaration on Human Rights article 25,1 asserts[245]:

> *Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.*

The UN International Covenant on Economic, Social and Cultural Rights, article 12 insists on a legal right to health care[246]:

> *1. The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*
> *2. The steps to be taken by the States Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for:*
> *(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;*
> *(b) The improvement of all aspects of environmental and industrial hygiene;*
> *(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;*
> *(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.*

The Council of Europe Social Charter (adopted 1961, revised 1996)[247] mentions health 26 times, most significantly in part 1, 11:*“Everyone has the right to*

---

[244] Most importantly I did not include the problem of scope and exact content of the right to health care. This is simply such a huge field that any adequate overview at this point would not have been possible. My aim was to look at the justificatory basis for the right to health care in principle, to find an answer to the question why should resources be set aside for health care in the first place? Only then can the discussion on resource allocation and priorities start.

[245] UN Declaration on Human Rights

[246] UN International Covenant on Economic, Social and Cultural Rights

[247] Council of Europe, *European Social Charter*, 1961; available at http://www.coe.int/T/E/Human_Rights/Esc/;accessed 13.05.2005.

benefit from any measures enabling him to enjoy the highest possible standard of health attainable."

Perhaps most famously, the World Health Organisation has outlined in its Constitution the following[248]: *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.* Health is in the document defined as *"state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"*.

All the above examples manifest a right to health care in some form or the other, mostly in the language of "attainable health" making it clear that health is even in this age of rapid medical progress something that eludes the possibility of human guarantee. This right is recognised or simply declared to exist.

But before focusing on justifications of the right to health care, it is necessary to underline that not all accounts about provisions or justice in health care attempt to formulate health care claims in the language of rights. This is usually explained by either of the two positions.

Firstly an understanding that the language of rights is unsuitable in the field of health care as it destroys the special ethical relationship between the health care provider and the patient. The concept of a virtuous physician is centred on the duty of a medical practitioner to do her utmost to provide for the medical needs of the patient. Thus the voluntarily accepted obligations of doctors towards their patients are the basis from which any claims or further considerations of justice may arise and it would be immoral to insist on the rights of patients or doctors[249]. This is not solely an argument against simply the utilisation of the language of rights but criticism is also levelled against the type of morality that rights-based discourse tends to entail, for example in grounding motivation. Thus from a virtuous physician point of view doctor's obligation to her patients grows out of her willingness and desire to care for them, to cure them because she wants to do it. The rights-based discourse would motivate her action in terms of her duty to care that arises out of patients' rights to require her services, changing the motivation from "wanting to care for others" to "having to do it". It is therefore alleged that the rights discourse would bring along a qualitative change to the worse in the doctor-patient relationship.

Secondly, there is an assertion that a right to health care that strives to be universal, or a human right, cannot be justified. Certainly accounts of negative rights that were discussed in the previous section assert this and would insist that health care needs perhaps *ought* to be fulfilled through benevolence, but that no such right can exist. There are also positions that deny the right to health

---

[248] World Health Organisation, *Constitution*, 1946; available from http://w3.whosea.org/LinkFiles/About_SEARO_const.pdf; accessed 12.05.2005.

[249] Laurence B. McCullough, "Justice and Health Care: Historical Perspectives and Precedents," in *Justice and Health Care*, ed. E. E. Shelp (Boston; D.Reidel Publishing Company, 1981): 60–65.

care but recognise some other positive rights (like education). Therefore it is maintained that the right to health care cannot be justified universally but a similar result might be obtained by a complex assemblage of arguments from special rights to health care (based on rectification or compensation), principle of harm prevention, prudential/utilitarian arguments and an odd concept of enforced benevolence[250]. A right to health care would necessarily involve the need to "translate the unfortunate to the unfair" and require a demonstration of how the state is justified in reallocating resources for the purpose of providing for those "wronged" by the disease[251] (I leave aside here the issues of personal responsibility towards one's health). Arguments for the coercive reallocation of resources for these purposes have been found wanting.

I will return to these criticisms after I have looked into the ways of justifying the right to health care. Although I will concentrate on two fairly close accounts, these do not exhaust the possibilities of justifying such a right. And it is unlikely that all diverse arguments for a right to health care fit together well to provide for one coherent set of justifications. Philosophy is good in providing a variety of answers to difficult questions but has a serious problem with providing just one answer. But perhaps this is not a weakness but strength.

4.3.1. Daniels' theory of just health care

One way of justifying a positive right to health care is to link it firmly with a theory of (social) justice. This way, a right is not a natural, independent phenomenon but its existence and scope is dependent upon agreements regarding resource allocations. One of the best-known accounts of justifying access to health care via a theory of justice has been developed by Norman Daniels[252]. His theory of just health care is in principle based on John Rawls' theory of justice but Daniels has developed his account further to include health care services into the basic institutions that are to provide for the equality of opportunity in the society. Rawls was rather of the opinion that health is a natural and not a social good whereas it is increasingly acknowledged that the

---

[250] Buchanan argues that enforced benevolence is needed to ensure coordination and effectiveness of benevolent acts. But this to my mind seems to conflict with one of the most important qualifications of benevolence, namely the possibility of choosing not to be benevolent. Allen E. Buchanan, "The Right to a Decent Minimum of Health Care," *Philosophy and Public Affairs* 13,1 (1984):66–78.

[251] Thomas J. Bole III, "The Rhetoric of Rights and Justice in Health Care," in *Rights to Health Care*, eds. T. J. Bole III and W. B. Bondeson (New York: Kluwer Academic Publishers, 1991): 2–4.

[252] Daniels, *Just Health Care.*

growing efficacy of medicine is turning health care more and more into a social good[253].

What kind of a social good is health care? What is the moral significance of this good? Daniels' argument for the moral right to health care is structured as follows:

i. The meeting of health care needs provides for the normal species-typical functioning.
ii. Normal species-typical functioning has an important impact on the individual's normal opportunity-range in a given society.

As most rights accounts, Daniels starts out by underlining the importance of human needs and interest in grounding the concept of a right. His focus is on health care needs and he discriminates between important and less-important needs by defining illness through analysis of biological data[254]. This data is then compared to species-typical normal functioning and in case of substantial deviations, a health care need is established. What Daniels aims at through such a definition is an objective account of health care needs that have to be objectively ascribable (it should be possible to assert that a person has a health care need even if she does not recognise it) and objectively important (this has to do with moral justification that only important needs have).

Whatever our aims and desires in life, normal species-typical functioning has a strong tendency to support us in achieving these goals or at least in moving towards them.

Deficiencies in normal species-typical functioning will thus have a negative effect in decreasing our opportunities to choose a life-plan or a suitable version of a good-life. Also, humans should have a possibility to change their minds during their life-course, and again species-typical functioning helps to assure that they

---

[253] The empirical data linking health/morbidity rate to socio-economic status is available from many countries. Simply put, this linkage means that people with higher socio-economic status also have better health. For an analysis based on UK and US data see Nancy Adler, Thomas Boyce, Margaret A. Chesney, Sheldon Cohen, Susan Folkman, Robert L. Kahn, S. Leonard Syme, "Socioeconomic Status and Health: The Challenge of the Gradient," in *Health and Human Rights: A Reader*, eds. Jonathan M.Mann et al. (New York: Routledge, 1999).

[254] There are serious problems with this solely biology-based approach to illness as much of the literature in medical sociology and sociology of health and illness amply demonstrates. Much is to be said to address the issues that for example Michel Foucault has discussed in uncovering the power/knowledge aspects of the medical enterprise. Although Daniels allows for some relativity in connection with social factors, he is ultimately of the opinion that species-typical functioning is a concept capable of founding a fairly universal basis. I will not however pursue this issue here, as I think that a better qualification of these terms could still in principle proceed the same route in terms of morally justifying health care provision. Michel Foucault, *Madness and Civilisation,* trans. R. Howard (London: Tavistock, 1975); *The Birth of the Clinic: An Archaeology of Medical Perception,* trans. A. M. Sheridan (London: Tavistock, 1976).

are able to do so. Our health care needs that assure this functioning are objectively important because they are the strategic foundation upon which the human interest in having and securing a normal opportunity-range in a given society depends. Health care institutions that are based on the principles of justice will thus be part of a social infrastructure that will provide people with the liberty and capability to make choices, including about the content of good life.

Access to health care is fundamental as it is the basis for the enjoyment of many other rights[255]. Illnesses influence our life: choices regarding "good life" diminish or even disappear. Just health care would thus provide for services that would maintain, restore or compensate for normal species-typical functioning. Providing for equal opportunities in this sense is the moral function of health care.

This argument is implicitly echoed in the HUGO Statement on Benefit-Sharing. It insists the following: *"Companies involved in human health may have special moral obligations"*[256]. While Daniels' theory is focused on the responsibilities of government, the HUGO statement refers to an increasing trend of commercialisation of medical research. Despite the different stress on responsibilities these positions concur in recognising the special moral significance of human health. HUGO statement adds that the responsibilities accompanying the morally sensitive sphere of medicine apply to any influential actors who are involved.

If this line of argumentation regarding the moral significance of health care services is accepted, it still does not in itself ground a right to health care. For this we need to further accept that equality of opportunity is an important value that should be supported. Daniels does not set himself the task to prove this but he does point to various theories in moral and political philosophy that are capable of providing this (and he himself has used Rawls' approach).

Before turning to criticisms of Daniels' theory, I will introduce a close alternative account that has been put forward by Amartya Sen and Martha Nussbaum. In my opinion their functioning or capability-based approach is fairly comparable to Daniels' in terms of moral reasoning, although Sen and Nussbaum are much clearer about the international relevance and possible applications of their thinking whereas Daniels is more nation-state-based. Nevertheless, I will be assessing the criticisms against these theories together, as it is the moral justification focused on the individual's life-plan that forms the core of both approaches.

---

[255] Of course it is possible to think of examples where someone's health status is irrelevant in his or her pursuance of a good life. That is why Daniels is careful to talk about a tendency to secure normal opportunity-range and not a guarantee for a good life.

[256] HUGO, *Statement on Benefit-Sharing.*

4.3.2. Sen-Nussbaum capabilities/functionings account

Sen's and Nussbaum's "capability ethic" has been a prominent approach especially in international development studies. While Sen is a Nobel price winner renowned for his sophisticated blending of economics and moral philosophy and Nussbaum is a Professor of philosophy and classics, their separate works as well as their cooperation have resulted in a moral theory that attempts to ground a basic social minimum in certain universal human capabilities[257]. Their focus is decidedly sweeping and health concerns are only part of the many issues they identify and grapple with.

Capability ethic is built around a basic social minimum that is described in the language of human capabilities. To clarify the relationship between capabilities and the oft used concept of functionings, they have asserted the following:

> "*The life that a person leads can be seen as a combination of various doings and beings, which can be generically called functionings. These functionings vary from such elementary matters as being well nourished and disease-free to more complex doings or beings, such as having self-respect, preserving human dignity, taking part in the life of the community, and so on. The capability of a person refers to the various alternative combinations of functionings /…/. In this sense, the capability of a person corresponds to the freedom that a person has to lead one kind of life or another"*[258].

A functioning is thus a basis for a capability, it is an opportunity to function in a selected way and thus constitutes an important part of person's freedom. To illustrate and explicate the idea of capabilities Nussbaum has produced a list of ten central human functional capabilities that she believes can be used on cross-cultural basis as the moral underpinnings of central political concerns[259]. The list includes also a number of health-related aspects[260]:

---

[257] Their views of course do not coincide in all details. For a comparative overview see David A. Crocker, "Functioning and Capability. The Foundations of Sen's and Nussbaum's Development Ethics," *Political Theory* 20, 4 (1992): 584–612. For a similar assessment by Nussbaum see Martha Nussbaum, *Women and Human Development. The Capabilities Approach* (New York: Cambridge University Press, 2000): 11–15.

[258] Martha Nussbaum, Amartya Sen, "Introduction," in *The Quality of Life*, eds. M. Nussbaum, A. Sen (Oxford: Clarendon Press, 1993): 3.

[259] Sen has distanced himself from this more normative and specific account. He does not necessarily oppose it but argues that the capability approach should be left open also to other interpretations and that this openness, "deliberate incompleteness" is an important characteristic of an entire account. Amartya Sen, "Capability and Well-Being," in *The Quality of Life,* 47.

[260] Nussbaum, *Women and Human Development*, 78–80.

1. Life. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. Bodily health. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.

There are also a number of other capabilities that have relevance in terms of health but these two above are most directly linked to health care concerns.

What is the moral significance of such a list? Capabilities constitute a core that is essential for allowing humans to live a truly human life. It is not a guarantee but it is a necessary condition, a minimum prerequisite, on the basis of which it is possible to choose and pursue a valuable life. Capabilities are universal, they belong to everyone, anywhere, based on the Kantian rule of a person constituting an end in herself. Also, human dignity is based on the fact of person being capable of moral choice. Upholding and strengthening this capability means providing for basic human needs and *vice versa* the fulfilment of those needs buttresses the possibility of moral choice. Denying this is only possible when one believes that contingencies, luck, good or bad fortune, have no effect on the chance of flourishing life[261]. Fulfilment of basic needs provides for the securing of capabilities that allows for various scenarios of human flourishing and choices for good life. Human being is accorded her dignity because she is capable of moral choice but moral choice is possible when the person has some basic needs fulfilled. Arguably, there is something about the absence of a human capability that disrespects in existential sense the worth and dignity of a human being. A person with an unfulfilled human capability cannot be fully human, or even "truly human" in Marxian sense[262]. Thus to treat a human as an end means to respect her capabilities.

Despite this Kantian vocabulary both Sen and Nussbaum assert in one way or another that their theory is relatively free of metaphysical underpinnings, that it is not a comprehensive but partial theory or doctrine[263]. Capability ethic is an approach that people with differing religious, cultural, metaphysical and other views should be able to embrace as a pluralistic basis, a minimum threshold from where the discussion only begins. As a pluralistic account, it does not rely on the possibility of agreeing upon one overarching value or principle and thus

---

[261] Nussbaum discusses the moral relevance of needs (but not all needs!) in *Fragility of Goodness*, 142–151.

[262] It is necessary here to refer to criticisms of disability activists and theorists who question the views of Nussbaum. The gist of their argument is that her definition of necessary capabilities for fully human life excludes many valuable lives of disabled people. Cal Montgomery, "Critic of the Dawn," *The Disability Rags. Ragged Edge Magazine Online* 2, 2001; available at http://www.raggededgemagazine.com/0501/0501cov.htm; accessed 26.08.2005.

[263] On Nussbaum see *Women and Human Development*, 5, 75–77. On Sen see Amartya Sen, "Justice: Means versus freedoms," *Philosophy and Public Affairs* 19, 2 (1990): 111–121.

a number of these are seen as equal with further prioritisation among the set neither feasible nor desirable. But the list of capabilities is not infinite and it cannot be claimed to be value-free. While Nussbaum generally agrees to be aligned with political liberalism, Sen has excluded utilitarianism and libertarianism as acceptable moral views[264]. Nevertheless, they hope to have provided a view that seeks universality while containing enough space for cultural and other specificities.

4.3.3. Right to health care — assessment and criticisms

I have outlined two theoretical approaches that strive to establish a right to health care. Although neither of them addressed directly the question "what makes life good", both are concerned with securing a sort of foundation from where diverse versions of good life can spring. The fulfilled capabilities are a necessary condition for the exercising of freedom which is a parallel idea to the normal opportunity-range in choosing one's life plan that Daniels focused on. In both theories the value of having a choice about the way in which one's life is lived, is expressed as a moral requirement that should be protected and fulfilled in the political arena. This is very much parallel to the reasoning that provided rationale for rights discourse.

The basis from where Daniels starts is more or less accepted by many strands in moral philosophy. The underlying idea of most rights-accounts, as argued by Gregory Vlastos, is that all humans have intrinsic moral worth that requires equal consideration and respect[265]. Even Nozick's "capacity for meaningful life" carries a parallel idea. Although Daniels' account is in principle based on the contractual theory of justice, he insists that the principle of equal opportunities that grounds his thinking does not unavoidably have to be based on Rawls. Utilitarians can also support this principle if the prevalence of diseases and illnesses results in the diminished overall utility or other relevant factor.

Nussbaum insists that a moral claim that certain human capabilities should be developed is "a freestanding moral idea" [266]. Human capabilities are a sufficient basis for political rights and give rise to correlated duties but they are also separate from any ideological, religious or other views. While Sen is careful not to relate capabilities explicitly to rights, Nussbaum does so openly by insisting that central capabilities are to be seen as types of side-constraints that cannot be violated in pursuit of other goals[267]. Capabilities are a basis from which citizens can make demands towards their governments (and possibly

---

[264] Crocker, "Functioning and Capability", 598.

[265] Vlastos, "Justice and Equality".

[266] Nussbaum, *Women and Human Development,* 83–84.

[267] Ibid.,14.

supranational entities?) and they are certainly parallel in content to both civil and political rights, as well as to second generation rights. But in an important way, capabilities can also be seen as grounding rights, similarly to the way human interests and needs were regarded a basis for rights in previous section.

A remark is also in order about the need to "translate the unfortunate into unfair" referred to in section 3.5. What is meant here is that fellow citizens cannot in all fairness be blamed for someone's illness and required to pay for it. While perhaps this issue is not best addressed in the language of blame, it is possible to query about the strong connection between socio-economic status and health as these have been found heavily linked in most countries. Also the increasing efficacy of medicine seems to relocate much of what used to be question of chance and luck into the realm of human decision-making. This development has been called "colonization of the natural by the just"[268] and it implies that the bounds of (social) justice might be changing as humans and societies are increasingly able to take action to address unfairness (like disease) and not simply accept it as given. Instead of unfairness in the sense that someone can directly be blamed, we might be dealing with unfairness also in cases where we are not to blame but are not responding to rectify harm provided that we are in principle able to. Consequently an important positive right like a right to health care does not in principle need a different justification from these that are grounding negative rights. Fulfilment or respect for certain human interests is the basis for both positive and negative requirements.

Aside from the challenges that question the appropriateness of positive rights in principle, the accounts of Daniels and Sen-Nussbaum have been reprehended from other positions. Firstly I will examine claims that challenge the universal and paternalistic implications of their accounts. Secondly, I will attend to an allegation that is linked to an already well-established discussion regarding the relationship between the right and the good in political philosophy.

1) The first challenge argues that capability ethics and also Daniels' just health care theory are plainly guilty of imposing so-called universal categories. The argument insists that such aspirations are unethical, as universalism is unfounded, or possibly, in the present case is simply Western ideals clothed in the language of universals (thus this is criticism towards all rights and similar concepts). The core of the cultural relativism argument is centred on an understanding that local, culture-specific values and practices cannot be morally judged from an external perspective. The validity of certain existing traditions and their justifications can only be decided upon from within a culture. The cultural relativist challenge against the universalism of human rights is a straightforward one — the application of such a framework is improper and immoral. The fact of value pluralism, and more importantly, the incommensurability of values, sets the stage for a recognition that universal aspirations necessarily involve unjust imposition of certain values onto various cultures.

---

[268] Buchanan et al., *From Chance to Choice,* 82–84.

Cultural relativism asserts that there exist systems of moral thought that differ but are equal in value and cannot be prioritised.

I think the main thrust of the cultural relativist position can be discussed via two arguments. The first is a descriptive assertion that rests on a fact that people in various countries and cultures live differently — value diverse things, accept distinct traditions. This argument supports relativism because it demonstrates that relativism simply exists. To refute this position it is possible to insist that a descriptive fact is not and cannot be a basis for morality as latter should rather be based on prescriptivity or what *should* be the case. Furthermore, the fact that universal rights discourse originated in the West, does not logically entail that its validity is limited by its place of birth[269]. Philosophically speaking, it is problematic to claim that the view of locals, or the "native self-understanding" is logically and by default more legitimate and true, than other perspectives[270].

The second argument for cultural relativism rests on the incommensurability of values thesis that emphasises the impossibility of the existence of only one version of the good and right. I will illustrate this line of thought with the so-called Asian values challenge, named so after the criticisms levelled against universal human rights from the academic and political circles of some South-East Asian countries. Rights discourse is charged of being overly individual-centred to the detriment of the community-based values like solidarity, the priority of the common good and respect for authority. Traditional sources for justice in some Asian societies like Buddhism and neo-Confucianism are rather patriarchal, characterised by the acceptance of inequality of relationships as natural where one side assumes prominence as a "father-figure" exercising rights in the interest of all. In a similar vein of value-preference social and economic rights have been deemed to be more important than political and civil rights by some Asian leaders who have insisted that curbing of the latter will increase economic efficiency and provide better for the overall satisfaction of social and economic rights[271].

To address this charge I propose to start by questioning the very notion of culture (and that of tradition) that is rather unproblematically utilised by many

---

[269] Although the language of rights was coined within one civilisation, the basis or at least the seeds for rights lie in the acknowledged needs and interests of humans, their well-being and dignity that is in one way or another present in most cultures. Human rights discourse may rather be associated with the arrival of modernity that historically appeared first in the West and not with some inherent Western qualities. The development of markets, the modern state and industrialisation were processes that inaugurated and accelerated this phenomenon firstly there. Jack Donnelly, *Universal Human Rights in Theory and Practice* (Ithaca: Cornell University Press, 2003): 58–60

[270] Xiaomei Chen, "Occidentalism as Counterdiscourse: He Shang in Post-Mao China," *Critical Inquiry* 18 (1992): 686–712.

[271] For example this has been argued by the one-time Singapore leader Lee Kwan Yew (known also as the Lee thesis).

relativists and surprisingly many universalists as well[272]. Culture is in many of those confrontational arguments implicitly taken to constitute a unified entity with certain values, practices and traditions explicitly graspable. But any culture never is so simply assessable. It is a hybrid, ever changing, continuously debated, contested and negotiated site of relations where sensitive issues of power should not be underestimated. Culture is not established solely in relation to or even in reaction to other cultures but it is an outcome of continuous struggles within it. What will be counted as a legitimate practice within a certain culture is a result of certain compromises or simply the imposition of the will of the more powerful within that specific context. A more or less homogeneous "way of life" might be identified for various purposes but on account of privileging one discourse over the many alternative dialogues, shared and contested visions and impositions surrounding it.

Also, many proponents of the Asian-values have been accused of plain party-politics in limiting the political and civil rights of their populations (how "traditional" is the modern coercive police-state that claims to be an outgrowth of local practices?)[273]. A critical stance upon the employment of traditions in these debates points to a very contemporary political and other interests that ground the insistent uptake of a carefully selected and conditioned piece of "tradition"[274]. Indeed, tradition itself, as it is evoked and applied nowadays, is a distinctly modern creation[275]. And its presentation as a settled and established "piece of evidence" is but a powerful appearance backed by specific interests

---

[272] Ann-Belinda S. Preis, "Human Rights as Cultural Practice: An Anthropological Critique," *Human Rights Quarterly* 18, 2 (1996): 286–315.

[273] Amartya Sen, "Human Rights and Asian Values," *The New Republic* 1997, 14 & 21; Kenneth Christie, "Regime Security and Human Rights in Southeast Asia," in *Politics and Human Rights*, ed. D. Beetham (Oxford: Blackwell, 1995); Daniel Bell, "The East Asian Challenge to Human Rights: Reflections on an East-West Dialogue," *Human Rights Quarterly* 18, 3 (1996): 641–667.

[274] I think one example would illustrate that argument well. This case is from India and concerns one quite extreme 'tradition', namely suttee or the widow-burning that has presumably been a practice in some areas. Suttee involves the voluntary suicide by the widowed wife. Investigation of Indian feminists has uncovered the very complex entanglement of political, economic and other interests responsible for producing a 'tradition' out of marginal, haphazard and rather recent events. They argue that suttee as a 'tradition' is a colonial construction arising from 19th century concerns of the British colonial rule engaging with the nationalist and religious demands of local stakeholders. The way in which such a 'tradition' has been literally created through cooperation among various interest groups aiming to strengthen their rule in practice and rhetoric, is a powerful reminder that calls to a critical examination of such claims. Uma Narayan. *Dislocating Cultures: Identities, Traditions, and Third-World Feminism* (New York: Routledge 1997): 41–80

[275] Fred Halliday, "Human Rights in the Islamic Middle East," in *Politics and Human Rights*, ed. D. Beetham (Oxford: Blackwell, 1995):162.

and concerns[276]. A view of cultures as constituted of confrontation and dialogue among other elements, would allow for a more nuanced and inclusive perspective that could challenge the simplistic us versus Other model so essential for cultural relativist argumentation. The fact that we are situated in our specific local context does not logically entail that there can be no shared values. Such incompatibility is perhaps easy to assume but it is in no way necessarily involved. Also, it is important to be reminded that value pluralism is not only an inter-cultural issue but very often present within one culture or at least civilisation.

While this cautious attitude towards the language of traditions is an important way of contesting many cultural relativist arguments, there is also a genuine possibility of value pluralism that cannot be accounted for via political and historical arguments. One way of dealing with the issue of value incommensurability is to layer the argument starting from more or less agreed understandings of certain notions or values on conceptual, abstract level. The differences can then be discussed on interpretation and implementation level and these of course can still be very substantial[277]. The notion of *relative universality* of human rights might seem oxymoronic but it entails a perception that some level of overlapping consensus can be achieved. While the shared understandings may be rather thin, they could be achieved on the level of substance while respecting divergence on other levels[278]. For example the infamous abortion debate can be reconceptualised from the question “Can killing humans be justified?” to “How do we define a human?” [279] The immorality of killing humans would then in a sense form a common ground, although a thin one.

While above I attempted to refute the challenge against universal categories especially in terms of rights discourse (but also applicable to the capabilities-approach), Daniels’ case is a bit more complicated and I will address it separately. While Daniels is applying the language of objective health care needs, he is careful to insist that the normal opportunity-range, that should be provided, is dependent on a given society. Thus it is justified that in poorer countries less health care needs can be dealt with in comparison with the more affluent countries. This link with the local contingencies makes a normal

---

[276] A bizarre example of contemporary interests mingling with the “traditions” concerns a consortium of Apache tribes who in their letter to US museums insisted on full control of the Apache cultural property including ”all images, text, ceremonies, music, songs, stories, symbols, beliefs, customs, ideas and other physical and spiritual objects and concepts “/../ including any representations of Apache culture offered by Apache or non-Apache people.” Michael F. Brown, “Can Culture be Copyrighted?” *Current Anthropology* 39, 2 (1998): 194.

[277] Donnelly, *Universal Human Rights*, 93–98.

[278] Ibid. ,98.

[279] This example is from David Resnik, *The Ethics of Science. An Introduction* (London: Routledge 1998) 31.

opportunity-range in a given society into a social artefact — what is considered normal is dependent, among other things, also on the local level and distribution of health care[280]. Daniels has been accused of sort of circularity here, as taking the normal opportunity-range as a basis might not be sufficient in many instances were this range is unacceptably low. He seems to be caught between two fires — on the one hand insisting that objective health care needs can be established universally (and being accused of firstly claiming that there exist such things and secondly, trying to impose them regardless of local contingencies), on the other hand claiming that these needs should be provided for depending on the local opportunity-range (and attacked for not supplying a strong enough basis for general criticisms of the local standards).

But Daniels argues that the inclusion of a society-specific opportunity-range is very important to allow for the fact that relevance of a specific illness varies in different societies[281]. An example of dyslexia might explain his position well, but I think that with the majority of widespread illnesses such society-specificity is much less true. More stress on the normal species-typical functioning in comparison with the society-specific opportunity-range would perhaps provide a way to overcome this circularity. On the other hand, I agree with Daniels that while health care services usually are capable of influencing the distribution of opportunities within the society, they have much less impact on the normal opportunity-range of the society, the latter is usually heavily dependent on other factors (e.g. distribution of wealth and educational opportunities).

2) The second line of criticism links to a substantial discussion in political philosophy having to do with the relationship between the concepts of the right and the good. The controversy is most often associated with John Rawls' theory of justice and since Daniels as well as Sen and Nussbaum have acknowledged the closeness of their views to that of Rawls, I will discuss his approach to the issue shortly.

The concept of the right is in this context usually identified with political considerations of justice, and most importantly with the establishment of just institutions. Rawls' "priority of the right" purports to be a solely political conception and not a comprehensive one, meaning that it establishes only certain political values and ideals and does not attempt to provide a fuller conception of the good life[282]. The good, on the other hand, has to do with filling up the space that has been limited by considerations of the right. The explication of the notion of good has been central to many general and comprehensive doctrines or theories (like religious or moral) that establish certain core values and virtues that should guide one's life. The proper role of

---

[280] Buchanan, "The Right to a Decent Minimum of Health Care", 64.

[281] Norman Daniels, "Fair Equality of Opportunity and Decent Minimums: A Reply to Buchanan," *Philosophy and Public Affairs* 14, 1 (1985): 106–110.

[282] Rawls, "Justice as Fairness", 223–251.

the right and the good according to Rawls is shortly: "justice draws the limit, the good shows the point"[283]. In his earlier writings Rawls insisted that he had only delineated the right and that the good will be up to everyone to decide upon (because no final agreement can be achieved on these matters). In his later writings he acknowledges that some potential versions of "good-life" are excluded from his conception, certainly those that do not respect the core values of political liberalism like individual freedom and equality.

One reason for this later clarification of the relationship between the right and the good, has to do with the challenges that have been raised towards his hugely influential treatise. He has also later asserted that his theory has no direct universal or metaphysical aspirations and it should be viewed as first and foremost relevant in the context of liberal, democratic nation-states. While I have no space here to go into the complex communitarian challenge[284], the most relevant critique in the present context insists that Rawlsian political conception of the right in fact seriously diminishes the available versions of the good life by its exclusive focus on the individual. Similarly, the issue for Daniels' and the capabilities approach is whether their foundations do not pre-determine the kind of good that is achievable. Normal opportunity-range and capabilities attempt to provide for the basis from where different versions of good-life can be chosen. But does it really allow for a variety of good-lives or does it prescribe a very limited range?

Daniels explains that although his account is roughly based on Rawls, the fundamental ideal of equal opportunities can in principle be justified by other accounts in political and moral philosophy. Sen and Nussbaum have also expressed their closeness to Rawlsian theory of justice, although they do have important disagreements and in principle the capabilities approach is much less centered around a theory of justice and more on the concept of well-being. As regards Rawls, both Daniels and Nussbaum revise his list of primary goods in including certain "natural goods" that Rawls excluded[285].

In a sense, the examined approaches would probably fall into the category of "objective list theories"[286] — Daniels with his objectively describable health care needs and certainly Nussbaum with her capability-listing (a system where

---

[283] John Rawls, "The Priority of Right and the Ideas of the Good," *Philosophy and Public Affairs* 17, 4 (1988): 252.

[284] For a comprehensive analysis of Rawls' theory of justice from a communitarian point of view, see Sandel, *Liberalism and the Limits of Justice*.

[285] An important difference is also that capabilities are individual-centered whereas in Rawls primary goods are qualities of institutions.

[286] Derek Parfit's account on what makes someone's life go best distinguishes between objective list theories, hedonistic theories (counts happiness) and desire-fulfilment theories. Parfit himself is of the opinion that the truth lies probably somewhere between hedonistic theories and objective list theorists. Derek Parfit, *Reasons and Persons* (New York: Oxford University Press, 1986): 493–502.

elements of facts and values are mixed[287]). Nevertheless, I think it is possible to argue that the scope for the potential good lives that these approaches outline is sufficiently wide and inclusive (although I do not doubt that philosophers are easily capable of coming up with the elaborated counter-examples of when this might not be so). But it is important to "put one's foot down" once in a while in philosophy, give up an attempt to provide an all-inclusive theory. Any apparent consistency that might be achieved through the mode of reasoning that attempts to be all-inclusive could well be a hoax as the results would "only have semblance of validity through leaving out all that they cannot calculate"[288] but which nevertheless are a constitutive and qualitative component of any life. Possibly some versions of good life are excluded, some life-plans not supported. But it can be at least a basis from where further discussions can start. Values needed for a good life might be incommensurable in principle which does not mean that we are always incapable of choosing between them in specific situations. Also the differences might not only be conflicting but can be complementing as well.

A conclusion from this section underlines that the right to health care is very much linked to an ideal of each and every person being provided with the real opportunity to choose her life-plan based on her understanding of good life. A right to health care, whether argued for through capabilities or the notion of normal opportunity-range, is not a guarantee of good life but a minimum level for allowing one to dream of and move towards one.

4.4. Rights in benefit-sharing — an assessment

The above analysis of the rights discourse has been rather theoretical and not much engaged with the actual problems and applications within benefit-sharing discussion. Nevertheless I have thought it important to highlight the fact that rights are a complex and contested concept on an abstract theoretical level and their utilisation in praxis involves challenges and difficulties. But I also aimed to provide a solid justificatory basis for a right to health care.

Now it is necessary to return to benefit-sharing and examine the applicability and appropriateness of rights in this context. I will first reflect somewhat on the issues discussed in chapter 1, pertaining to the conflicting discourses of profit-oriented market and that of human needs and equality. It is in this confrontation that I think the rights-based arguments to be most substantial and potent.

Secondly I will examine the subject matter of responsibilities. The respect, support and fulfilment of rights have traditionally been duties of states. The

---

[287] Thomas Scanlon has proposed such a descriptive parallel to the notion of "functionings". Scanlon, "Value, Desire, and Quality of Life," in *The Quality of Life,* 198.

[288] Charles Taylor, "The diversity of goods," in *Utilitarianism and Beyond,* 143.

powerful actors in genetic research and international trade like corporations seem therefore to be "off the hook" within the rights-centred approach, especially concerning positive rights. This renders the usefulness of rights discourse in benefit-sharing problematic unless one is willing to challenge the ingrained assumptions regarding the duties and responsibilities of non-traditional actors in securing rights.

4.4.1. Merging local and universal concerns

In this chapter I have argued for the positive right to health care as a possible justification for benefit-sharing in human genetics. Or to be more precise, I have argued for the justification of a right to health care but there is still something to be said regarding the application of this right within benefit-sharing. In Chapter 1 I aimed to demonstrate how various discourses have merged and provided for the emergence of benefit-sharing as a universal concern. From a largely property-centred compensation schemes in agricultural biotechnology to the principles of non-maleficence and beneficence of medical ethics, universal benefit-sharing attempts to address additional concerns arising from the vulnerability of the human condition. The shift from property and patenting rights to a right to health care includes a shift from commodification discourse to that of equality, solidarity and positive rights.

I think it is important to make that step into a more powerful discourse. There is a necessity for a stronger language in benefit-sharing for it to reach out of the "*shall be shared*" rhetoric into actual implementation. Rights-language is perhaps best equipped to do that and its wider utilisation directs us to further rethink the role and responsibilities of science and research in the present world. Developments in genetics but also life sciences in general are too influential to be discussed solely within the traditional frameworks of science governance. Calls have been made to democratise science, to apply a novel framework of responsibility to the undertakings that have outgrown their confined "laboratory-spaces"[289]. But it is not only the "taming" of research but an equally serious engagement with free market forces. The fast pace of commercialisation of biotechnology has meant that the rules of the game of market (the priority of profit and patenting, the distributive principle of desert) have installed themselves as a matter of course within an ever-increasing domain. But this is not a force of nature that cannot be engaged with. The insights from moral philosophy regarding the basic needs and interests of humans are one important source for subverting these tendencies and rights discourse is well equipped for

---

[289] See for example Sheila Jasanoff, *Designs on Nature. Science and Democracy in Europe and the United States (*Princeton: Princeton University Press, 2005); Philip Kitcher, *Science, Truth and Democracy* (Oxford: Oxford University Press, 2001).

challenging the implicit priorities and principles that have established themselves within commercial biotechnology.

At the same time it is also necessary to open the issue of new medical technologies to other disciplines besides bioethics, which has so far largely dominated the field. While bioethics has contributed significantly to the assessment and discussion around biomedicine and –technology, it should not constitute the only source for governance and policy development in the area. Overwhelming focus on the individual level (often conceptualised as essentially confrontational with societal anxieties) might limit the necessary uptake of other concerns and viewpoints. A more inclusive and extended discussion on benefit-sharing, on its basis, justifications and implementation, is imperative. Rights are a shared discourse between moral philosophy and politics, as well as an important instrument in debates on democracy and governance both on national and international levels, so there is potential for a stronger and broader effect in challenging the market paradigm.

A right to health care as a universal human right is very much non-contextual, existing independently of contingencies, and for example of the objectives, rationale and outcome of genetic research. Thus focus on human rights language also shifts the issue of responsibility. Once benefit-sharing discussion leaves the context of medical research or specific local agreements it is not anymore an issue involving only research agencies, pharmaceutical corporations, particular local and perhaps national governments. Once we are focusing on the rights language, especially human rights, the entire issue becomes of universal relevance. After all, disrespect towards human rights is not a local problem. It might be asked then how justified or useful is it to connect a rather specific line of thought like the sharing of benefits of genetic research with the grand rights-claims of global implications?

I have argued that benefit-sharing should be discussed on two levels and that some arguments, responsibilities as well as solutions only make sense on local research level[290], others only on universal one. But differentiating between specific and universal benefit-sharing for the sake of clarity of arguments, does not entail that these levels are not linked in important ways. Genetic research, the political, social, economic and symbolic claims, possibilities and problems that are contained in this field, is a domain that exemplifies the many significant issues that characterise our world today. The structural actors — global economic regulations and corporations, nation-states with their interests, the difficult baggage of colonial history, all do play a part in both contexts but the possibilities for engaging with these actors differ. While the impulse for commencing the debate on benefit-sharing lies in the particularities of genetic

---

[290] Although nowadays often research cannot be pinpointed to a location — while some of the sources for a new drug might originate from a poor developing country, the scientists are from diverse countries, the labs are located in some industrial nation and the final product might target a medical condition specific to another locality.

research, these considerations are to a large degree reverberating concerns from a much wider and complex global situation.

4.4.2. Reconceptualising responsibility

If benefit-sharing is to be justified via right to health care, then who is responsible for fulfilling that right? Traditionally the securing of rights has been the responsibility of nation-states, rights being part of their legislation or the states having agreed to germane international conventions. The WHO constitution states that *"Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures"*. While this statement indicates the moral responsibility of governments (WHO document is not a legal treaty and thus addresses unlimited audience in non-enforceable manner), right to health care is also a widely established legal obligation[291]. Traditional nation-state based theorising limits the scope of such obligations based on the implicit notion of (social) contract. Citizens have a collective responsibility within their state to ensure that basic rights are respected but no such duties to those outside the state borders are recognised as enforceable.

Within this governmental obligation, the right to health care is no special argument in benefit-sharing discussion, since it is independent from it. A human right should be fulfilled regardless of whether genetic research is ongoing or not, governments have the duty to provide health care services[292]. But benefit-sharing debate is not primarily fuelled by demands against governments. Rather two sorts of claims regarding responsibilities can be distinguished.

Firstly and obviously, large pharmaceutical companies have been at the centre of benefit-sharing debates and their responsibilities in non-human genetics as well as within specific human genetics research projects are increasingly established. But how can a right to health care argument be implemented in this context? Of course large corporations, becoming increasingly powerful actors in the world, should not disrespect (human) rights but currently the safeguarding and providing of these rights has been the responsibility of states. One possibility to argue for the responsibility of pharmaceutical industry would be to insist on the recognition of human health as a morally sensitive area that creates responsibilities for all those actors who are influential in this respect[293]. In a sense benefit-sharing discussion might

---

[291] See for example the UN International Convention on Economic, Social and Cultural rights.

[292] Although in some more affluent countries, the developments in genetic research might well influence the content of the health care services.

[293] This is the reasoning behind Daniels' account as well as that of the HUGO *Statement on Benefit-Sharing.*

mark the beginning of such tendencies. When HUGO ethics committee suggested that certain benefits should be shared by companies, then this is already an argumentation originating from outside the strict logic of market economy and traditional political duties. HUGO has suggested that our common genetic heritage as well as values like solidarity and justice should be and can be the rationale for benefit-sharing duties for both non-profit as well as for profitable enterprises. While this insistence does not make use of the rights language, it should not exclude it either.

Why not to insist on the rethinking of traditional responsibilities as regards rights? It could be argued that due to globalisation (nation-states relatively loosing their power to supra-national entities like corporations and international organisations) certain responsibilities should be re-appraised. Moreover, many morally important issues in the world today cannot be compartmentalised in the nation-state based units that philosophers have grown accustomed to. The obvious case of environmental pollution has already been established grounding moral and legal concerns from a wider perspective. But globalisation and the growth of transnational corporations are further examples of these new challenges. People's lives are profoundly influenced by actors they have no influence over. Of course, this has been the case with misfortunes as well as luck throughout human existence but the latter are a distinct category from enterprises established and governed by humans. The way international trade is organised nowadays, or medical research priorities are set, is not determined by natural laws and it can be changed. Obviously, moral arguments might only go so far with for-profit organisations. Therefore political engagement and rule-setting as well as economic incentives have an important role to play.

But in the larger scheme of things, redistributional activities of for-profit organisations (even if based on the rights-language) will not amount to a sufficient effect to tackle the issues that underlie the argument for benefit-sharing. Traditionally, responsibilities for protecting and fulfilling rights have lain with governments. For instance, it should be the responsibility of governments to protect the rights of their citizens via securing adequate benefit-sharing schemes with researchers and sponsors. This way the responsibility for fulfilling the right stays with the government but influences the content of benefit-sharing arrangement and includes companies. Various conventions and agreements regarding benefit-sharing within non-human genetic research have provided significant opportunities to help the developing countries advance a common argument in that domain.

On the other hand, emphasis on the human rights discourse would require the re-thinking of global policies and obligations on the basis of more or less stringent moral universalism. In that vein also national borders are no argument in limiting our obligations towards other humans (nor in limiting the obligations of our governments towards other governments and other human beings). If a right to decent health care arises from a *human condition* — our vulnerabilities, our capacity for moral choice and the relevance of need fulfilment for exercising of that choice, then this is a condition shared across the globe. It is ultimately inconsistent to link such an important right to an arbitrary fact like someone's birth-place. From the legal side, responsibilities of governments towards other governments and towards citizens of other states have found their way into international documents. General Comments on the International Covenant on Economic, Social and Cultural Rights insist:

> *"States parties have to respect the enjoyment of the right to health in other countries, and to prevent third parties from violating the right in other countries /…/ [States] should facilitate access to essential health facilities, goods and services in other countries, wherever possible, and provide the necessary aid when required.*"[294]

This very same responsibility before other governments and non-citizens that can be argued for on the basis of moral universalism, can also be supported through arguments attentive to present contingencies. The well-off countries (and their citizens) should critically reconsider the role that their governments play in perpetuating global inequalities[295]. Reflections on the morality of practices that are motivated solely in terms of furthering the interests of their own citizens are needed.

So what are we to do in a situation, such as the one presently, where clearly the rights of millions of people are not fulfilled? In many cases this has not to do with the scarcity of resources both in the global scale as well as in local contexts but with the distribution of these resources. Sen's work has been especially important in terms of pointing out that the beloved excuse of philosophers about resource scarcity in limiting important claims is empirically unfounded in many cases of hunger and deprivation. It has rather been the lack of entitlements to food, health care and other necessary goods that has contributed to these disastrous events and not resource scarcity as such[296]. Sen's conclusion that there are political and not economic reasons behind severe deprivation points to an important judgement regarding the significance of political claims. It is in this context of lack of entitlements (and not lack of resources) that I would highlight the relevance of rights discourse. If it is indeed

---

[294] UN Economic and Social Council, *The right to the highest attainable standard of health. General Comment No. 14, 2000: available from http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En?OpenDocument; accessed 16.08.2005; §39.*

[295] This is the central argument of Pogge who criticises the egoistic behaviour of governments of wealthy nations (e.g. the EU, USA, Australia and others) in disregarding the important interests and rights of those "outside". Pogge, *World Poverty and Human Rights*. The same is argued in UN Human Development Report 2003, especially chapter 8 "Policy, not charity: what rich countries can do to help achieve the Goals".

[296] Amartya Sen, *Poverty and Famines: An Essay on Entitlement and Deprivation* (Oxford: Clarendon Press, 1981).

so that deprivation is not due to resource scarcity, the insistence on the rights of people to basic food, health care and education can play a more consequential role. International organisations and increasingly NGOs have a role to play here[297].

---

[297] Examples of international collaborations between governments, international organisations, NGOs, private sector and communities include The Global Fund (to fight AIDS, Tuberculosis and Malaria) and Global Alliance for Vaccines and Immunisation (GAVI).

CONCLUSIONS

This work has focused on ways of justifying the concept of benefit-sharing, the latter having become one of the most important ethical concerns within biomedical research in its international setting. While the principle of benefit-sharing is well established in international documents, its rationale especially in human genetics, has not been systematically examined. What is owed to those participating in human genetic research? How can this concept and the ensuing practices be argued for? Can this be conceptualised in terms of charity, justice or within some other theoretical framework? Is anything owed to those not participating in specific research projects but claiming benefits based on the principle of need or human rights? The present work has undertaken to provide conceptual clarification and analysis of the notion of benefit-sharing and to discuss the possible lines of justification for the employment of this conception.

One of the central arguments of my work has been the elaboration of benefit-sharing as a multi-level conception. The differentiation between specific and universal levels of application is not only based on the historical development of this notion but also on the inherent justificatory foundation. Benefit-sharing on a specific level is a scheme limited to distinctive research projects and geared towards those who participated. Within traditional biomedical research, benefits to participants were based on the framework of justice as reciprocity, and the contributions as well as possible sacrifices of each were central to the logic of sharing. However, this largely desert-based distributive principle can no longer be sufficient if benefits to a larger community or population are insisted upon. What is the rationale behind the calls for sharing the benefits of research with the wider community or making research results available to all who might need them?

The first chapter of the work provided an overview of the main aspects of benefit-sharing discussion in human genetics. Benefit-sharing as such has been a well-established principle in many international documents: from the indefinite rhetoric of the United Nations International Convention on Economic, Social and Cultural Rights (stating "*the right of everyone to enjoy the benefits of scientific progress and its applications*") to the much more detailed account put forward in the United Nations Convention on Biological Diversity, to specific treatises devoted to the very subject in human genetics (HUGO Statement on Benefit-Sharing). Thus various international regulations and declarations do converge in recognising the importance of this issue but further elaboration on the rationale and explicit content of this notion is often lacking.

My analysis of the history and conceptual underpinnings of benefit-sharing uncovered three sources behind the present application of this notion. First the concept was put into practice in non-human biological research, where it was mostly associated with the struggle to end biopiracies and the patenting of various plant and animal resources without proper regard to the contributions of local populations or without recognising biological resources as belonging to communities or nations. This type of benefit-sharing is characterised by the distributive principle of desert, where the local populations have had a legitimate claim to a share based on their contribution in developing and nourishing a certain valuable biological entity or based on the recognition of this entity as their property (and thus them having a right to it). Another important aspect of benefit-sharing in this context pertains to a recognition that the sharing should be done among a community or population as a beneficiary.

When benefit-sharing became a relevant concern in biomedical research, it necessarily included aspects that have traditionally characterised the relationship between the researcher and the research participants. Well-established ethical principles like the duty to avoid harm (non-maleficence) as well as the duty of beneficence provided substantial rationale for benefit-sharing within this largely altruism-based setting. Additionally, much of medical research is characterised by the fact that in order for research to proceed, participants have accepted certain risks and inconveniences. Their direct contribution in this manner thus warrants the appropriateness of justice as reciprocity. In parallel with the benefit-sharing rationale of non-human biological resources, it is possible to refer to a sense of desert characterising the principle upon which distribution of benefits can be based. On the other hand, the fact that the volunteers as risk-takers are clearly identifiable, also limits the number of recipients or the number of those who have deserved some benefits in return for their contribution. The logic of correspondence prevalent in traditional medical research can justify benefit-sharing, but only within specific research projects.

The introduction of the concept of universal benefit-sharing entails several important changes into the justification and employment of this notion in comparison with the two previous applications. Universal benefit-sharing is a framework addressing concerns from a much wider background than the ethical issues arising from specific research projects. It aims to engage with the issues of global justice, thus not responding only to fairly limited concerns of separate research projects but occupied with the way access to research results is provided or denied to everyone else. These worries are sustained by the way research results have been largely unavailable to the majority of the world population. This is due to various reasons — e.g. the high cost of novel drugs and therapies, the patenting of research results that limits access, as well as the way research priorities are skewed towards the interests of the affluent nations.

The rise of the concept of universal benefit-sharing is strongly linked to several significant contingencies. Commercialisation of medical research has meant that increasingly investments originate from the for-profit sector whereas historically medical research has been funded by non-profit and governmental organisations. This transformation has had important consequences for the content of research and it has also raised important ethical issues. The decision for undertaking certain research has traditionally been guided by human needs. While human need continues to play an important role in steering research priorities, research itself discriminates heavily among those existing needs. There are also tendencies that suggest the inclusion of also other competing principles. For instance, for-profit research is significantly influenced by economic reasoning resulting in research into areas that promise high profits. Dire human needs are no longer the overwhelming cause for commencing research and this change undeniably has had an effect on the overall ethical environment of medical research.

A second substantial contingency concerns the phenomenon of globalisation. The coupling of medical research with the influential global market forces has produced a novel setup where benefit-sharing has acquired a different scope. The traditional reciprocal and also assumedly altruistic relationship between researchers and research participants has somewhat receded before the logic of marketplace where the distributive principle of desert and the motivation of a rational egoist matter most. Globalisation has also meant that a lot of human genetic research is undertaken in developing countries. This has raised concerns regarding the ethical safeguards protecting the interests of the local participants in securing that they would also be able to reap the benefits of successful research and not only bear the burdens. For example, an increasingly important consideration in conducting clinical trials in developing countries is that research undertaken should be responsive to the health care needs of local populations. Otherwise research participants would only bear the risks and burdens of research, the results of which would be of no relevance to their condition. Calls for universal benefit-sharing have hoped to address these concerns.

Thirdly, I have suggested that the conceptual enlargement of the benefit-sharing principle has been necessitated by the intrinsic qualities of genetics. Genetic information is by nature shared and the collection, storing and processing of that information necessarily involves people who might not have participated in research in the traditional sense. A good example illustrating the increasing complexity of human genetic research and the surrounding concerns is the establishment of large (population-based) human genetic databases. While the participants of these databases can be identified, the relevance of strictly reciprocal logic is questionable for several reasons.

As genetic information is shared by relatives, this challenges the applicability of traditional categories of medical ethics and law — the interests, the privacy and personal information cannot be neatly departmentalised and attached to the category of a single individual. Secondly, genetic information has predictive value and the potential to foretell certain health risks may harm the interests of people and make them vulnerable. The harm may be psychological as in frustrating the desired life plans when serious predisposition towards a disease is predicted. Or harm might be detrimental towards one's social activities by shutting off career options when employers or insurance companies learn of potential health risks. Overall, research involving genetic information necessarily involves people other than those directly participating.

For these diverse and substantial reasons, the concept of universal benefit-sharing would have to depart from the more contextualised rationales of sharing characterising this undertaking within non-human genetics and traditional medical research. This is why concepts like solidarity have been put forward to provide an alternative rationale for distributing the benefits in a more inclusive manner. The UNESCO Universal Declaration on the Human Genome and Human Rights has recognised the fundamental unity of humankind manifested in our sharing of the genome and suggested the linkage of this unity to the concept of human dignity and diversity. The concept of benefit-sharing as universal is a complex combination of these previous applications but including also the additional humanistic ideal of responding to human needs and respecting the principle of equality.

The rest of my work has been devoted to the examination of three possible justificatory routes for the benefit-sharing concept, with special focus on the universal application level. The second chapter investigated the concept of solidarity as a possible reasoning behind benefit-sharing. Solidarity has been suggested to be a relevant principle in benefit-sharing, especially as regards the sharing of research results to those not directly participating. For example, the HUGO Statement on Benefit-Sharing has insisted on relevance of solidarity in promoting health universally. However, the concept of solidarity as employed in bioethics literature has lacked clear formulation. In political philosophy solidarity has been traditionally identified with communitarian thinking, often to the exclusion of other approaches. In examining the conception of solidarity I argued for its pertinence also in liberal contractualism and benevolence-based discourses. Investigation into the possible definitions of solidarity brought out three important aspects of this notion for the purposes of universal benefit-sharing.

Firstly, the motivational relevance of both rational considerations and emotional reflections in grounding solidarity should be recognised. This is necessary both instrumentally (for example both rational and emotional attachments have an important and often indispensable role in prompting people to take action) as well as intrinsically (acknowledging the moral value of feelings as well as reasoning). Secondly, solidarity as a concept is by default characterised by certain dichotomy — one is always in solidarity with someone to the assumed exclusion of others. This can complicate the applicability of this notion on a wider, more inclusive level. While it is commonplace to be in solidarity with our communities or even nations, it is more difficult to extend this principle to embrace for example the whole of humanity. In order to save global solidarity from the fate of an oxymoron, the recognition of a fundamental universal interdependence is crucial. While the human genome provides a “scientific” rationale for such a proposition, the process of globalisation has illustrated the significance of this dependence in political, economic, social, cultural and other spheres. Finally, the fact that concerns of solidarity and justice often overlap, should be construed as beneficial, as this allows for the conceptualisation of a number of issues through either of these discourses, therefore achieving a certain complementarity that can be advantageous for the successful praxis of benefit-sharing.

The third chapter examined the consequentialist argument for benefit-sharing. Central to this discussion was Peter Singer's negative consequentialist principle of avoiding harm. The global relevance of this principle had been much debated in the context of large-scale famines mostly in Africa during the 1970s and 1980s. While the duty to avoid harm is intuitively appealing, problems arise with the practical application of this obligation. Namely, the principle seems to be too demanding — after all, we are always in a position to avoid some harm and the dutiful following of this maxim would not allow us to engage in any other projects of our life. Traditionally the duty-charity delineation has allowed for space in exercising the principle of avoiding harm. However, this delineation is generally conceptualised in terms of rights — respect for rights relegates actions under duty, non-applicability of the rights discourse assigns actions under charity. But the inclusion of the language of rights changes the consequentialist argument already by defining the avoidance of harms through respect towards rights (harm equals violation of rights).

If to be applied within benefit-sharing, the consequentialist principle needs to be limited whether "unorthodoxly" through the rights discourse or some other way. One possibility for elaboration and specification of the consequentialist duty to avoid harm in the benefit-sharing context could well lie in the inclusion of empirical data: for example prioritising among harms could be based on what sorts of harms are currently prevalent or are being foreseen as potentially serious in the future. Because consequentialism is traditionally very attentive to empirical data, the focus on context might be a potential solution in limiting our obligations. Additionally, historical experience also testifies to the fact that moral argumentation has undergone important changes and that the duty-charity delineation is in fact, in constant turmoil not only philosophically speaking but also in relevant applications in the field of law and politics.

In the fourth chapter I engaged with perhaps the most powerful instruments in political philosophy, namely rights, to assess a possible line of justification that could make use of these tools in benefit-sharing discussions. Rights being a very substantial as well as a contentious subject matter, I aimed to take this argument step by step and to provide an overview and discussion of certain fundamental aspects of the rights discourse. While there is no such thing as a right to benefit-sharing, it is still possible to utilise the rights discourse indirectly by insisting on a connection between the enforcement of certain existing rights and the goals of benefit-sharing. For instance, if benefit-sharing debate argues for a provision of access to various drugs and treatments that would allow people to cure debilitating illnesses (and consequently have a better chance of pursuing good life), then this in principle serves the same objective as the right to health care services.

Right to health care is indeed one possible starting point for argumentation in benefit-sharing, especially so because overwhelmingly benefits arising from research are medicine-related. A right to health care is traditionally categorised as a positive right — a right that would insist upon others to take up an activity, do something towards a right-owner. While positive rights have been increasingly recognised in law and practice, it is still a much debated issue in political and moral philosophy. Can positive rights be justified? Against some important lines of criticism arising mostly from libertarian philosophy I argued that positive rights are a philosophically feasible project, even if one starts to reason from the libertarian premises. The discussion proceeded through three arguments — I examined (and refuted) the so-called historical baggage, pragmatic and moral arguments against positive rights.

Granted that positive rights are justified in principle or at least there are no sufficient arguments for the strict delineation of positive and negative rights, I proceeded to argue for the right to health care as significant within the benefit-sharing discussion. Both the theory of just health care of Norman Daniels as well as the capability/functionings account of Amartya Sen and Martha Nussbaum, concur in the idea that the attainment of certain level of health is essential for having a possibility to live a good life. Daniels argues through the concept of normal opportunity range that should be guaranteed also by the availability of health care services. The principle of equality requires that each person should have a chance to define and follow her version of good life. Similarly Sen and Nussbaum insist on certain functionings (only some of these relating to health care) that are a basic minimum for allowing a person to choose and pursue a valuable life.

Several criticisms have been levelled against these accounts. Certain universal and perhaps even paternalistic implications have been identified within the discourse of rights. One of the most serious allegations against Daniels' and Sen-Nussbaum accounts relates to an already well-established debate concerning the relationship between the right and the good in political philosophy. Namely, it is argued that the theoretical frameworks proposed by these accounts privilege a limited range of versions of good life and are not the neutral starting points wherefrom it would be possible to have a real open choice. Daniels' account is largely based on a theory of justice of John Rawls and Sen — Nussbaum have also acknowledged the theoretical closeness of their approaches to that of Rawls.

Rawls has argued for the distinctness of the right and the good — while the right establishes the basic framework of a just society through mostly legal norms, the good pertains to the choices that individuals make to fill this framework. The central claim of Rawls has been the assertion that his political conception of justice and of the right, does not significantly limit the number of available good lives, although it certainly does not guarantee absolute freedom. I have argued for a position that recognises the situatedness of these theoretical accounts. But this should not be interpreted as a weakness but on the opposite, as strength. By way of conclusion I hope to have demonstrated that the right to health care is very much linked to an idea of each and every person being provided with the real opportunity to choose her life-plan based on her understanding of good life. A right to health care, whether argued for through capabilities or the notion of normal opportunity-range, is not a guarantee of good life but a minimum level for allowing one to dream of and move towards one.

The argument for the moral necessity of providing people with the basic opportunity to live a good life (as they define it) is central to the recognition of the right to health care. The rationale of this right is parallel to the concerns underlying the concept of universal benefit-sharing. Thus justification for the practice of universal benefit-sharing parallels reasons that have been at the core of moral and political philosophy for a long time. I concluded that human rights discourse can play an important role in benefit-sharing in its more universal aspirations. Human rights are an established and internationally recognised framework and the employment of rights discourse in benefit-sharing has the potential to highlight the serious concerns that otherwise might remain behind the less-engaging rhetoric. Additionally, I argued that there is need for reconceptualisation of traditional political responsibilities as regards human rights as well as a need to rethink the relationship between science and society to take into account the contingencies of commercialisation and globalisation that increasingly influence the objectives as well as the ways of biomedicine. Also, due to the fact that much of deprivation is caused by political determinants, the employment and application of the language of rights has strong potential in remedying the situation (as the origins lie in lack of entitlements and not resource scarcity as such). Overall, I hope to have underlined the need to rethink benefit-sharing in more strongly political terms in order to challenge the market ideology that has installed itself within biotechnology and related fields.

REFERENCES

Academic literature

Adler, Nancy, Thomas Boyce, Margaret A. Chesney, Sheldon Cohen, Susan Folkman, Robert L. Kahn and S. Leonard Syme. "Socioeconomic Status and Health: The Challenge of the Gradient." In *Health and Human Rights: A Reader*, edited by Jonathan M. Mann, Sofia Gruskin, Michael A. Grodin, George J. Annas. New York: Routledge, 1999.

Aiken, William, Hugh La Follette, eds. *World Hunger and Moral Obligation*. New Jersey: Prentice-Hall, 1977.

Aristoteles. *Nikomachose Eetika*. Edited and translated by Anne Lill. Tartu: Ilmamaa, 1996.

Aristotle. *Politics*. Edited by Stephen Everson and translated by Benjamin Jowett. Cambridge: Cambridge University Press, 2000.

Arthur, John. "Rights and the Duty to Bring Aid." In *World Hunger and Moral Obligation,* edited by William Aiken and Hugh La Follette. New Jersey: Prentice-Hall, 1977.

Barry, Brian. *Theories of Justice*. Vol.1. Berkeley: University of California Press, 1989.

Bell, Daniel. "The East Asian Challenge to Human Rights: Reflections on an East-West Dialogue." *Human Rights Quarterly* 18, 3 (1996): 641–667.

Bentham, Jeremy. *Rights, Representation, and Reform — Nonsense upon Stilts and Other Writings on the French Revolution*, edited by Philip Schofield, Catherine Pease-Watkin and Cyprian Blamires. Oxford: Clarendon Press, 2002.

Bentham, Jeremy. *The Principles of Morals and Legislation*. New York: Prometheus Books, 1988.

Berg, Kåre. "The Ethics of Benefit-sharing." *Clinical Genetics* 59 (2001): 240–243.

Bergmark, Åke. "Solidarity in Swedish Welfare — Standing the Test of Time?" *Health Care Analysis* 8 (2000): 395–411.

Bole, Thomas J. III. "The Rhetoric of Rights and Justice in Health Care." In *Rights to Health Care*, edited by Thomas J. Bole III and W. B. Bondeson. New York: Kluwer Academic Publishers, 1991.

Brown, Michael F. "Can Culture be Copyrighted?" *Current Anthropology* 39, 2 (1998): 194.

Brush, Stephen B. "Bioprospecting the Public Domain." *Cultural Anthropology* 19, 4 (1999): 535–556.

Buchanan, Allen, Dan W. Brock, Norman Daniels, Daniel Wikler. *From Chance to Choice: genetics and justice.* Cambridge: Cambridge University Press, 2001.

Buchanan, Allen E. "The Right to a Decent Minimum of Health Care." *Philosophy and Public Affairs* 13,1 (1984): 55–78.

Busby, Helen. "Blood Donation for Genetic Research: what can we learn from donor's narratives?" In *Genetic Databases. Socio-ethical issues in the collection and use of DNA,* edited by Richard Tutton and Oonagh Corrigan. New York: Routledge, 2004.

Caulfield, Timothy. ”Regulating the Commercialisation of Human Genetics. Can We Address the Big Concerns?" In *Genetic Information. Acquisition, Access, and Control*, edited by Alison Thompson and Ruth Chadwick. New York: Kluwer Academic/Plenum Publishers, 1999.

Chadwick, Ruth, Adam Hedgecoe. “Commercialisation of the human genome.” In *A Companion to Genethics*, edited by Justine Burley and John Harris. Oxford: Blackwell, 2004.

Chadwick, Ruth, Kåre Berg. “Solidarity and equity: new ethical frameworks for genetic databases.” *Nature Review Genetics 2 (*2001): 318–321.

Chadwick, Ruth, Sarah Wilson. “Genomic databases as global public goods?” *Res Publica* 10, 2 (2004): 123–134.

Chen, Xiaomei. “Occidentalism as Counterdiscourse: He Shang in Post-Mao China.” *Critical Inquiry* 18 (1992): 686–712.

Christie, Kenneth. “Regime Security and Human Rights in Southeast Asia.” In *Politics and Human Rights*, edited by David Beetham. Oxford: Blackwell, 1995.

Cranston, Maurice. “Human Rights, Real and Supposed.” In *Political Theory and the Rights of Man,* edited by D. D. Raphael. London: MacMillan, 1967.

Crocker, David A. “Functioning and Capability. The Foundations of Sen’s and Nussbaum’s Development Ethics.” *Political Theory* 20, 4 (1992): 584–612.

Daar, Abdallah S., Halla Thorsteinsdóttir, Douglas K. Martin, Alyna C. Smith, Shauna Nast and Peter A. Singer. “Top ten biotechnologies for improving health in developing countries.” *Nature Genetics* 32 (2002): 229–232.

Daniels, Norman. “Fair Equality of Opportunity and Decent Minimums: A Reply to Buchanan.” *Philosophy and Public Affairs* 14, 1 (1985): 106–110.

Daniels, Norman. *Just Health Care*. Cambridge: Cambridge University Press, 1985.

Deacon, Bob. *Global Social Policy: International Organisations and the Future of Welfare*. London: Sage Publications, 1997.

Dean, Jodi. “Reflexive Solidarity.” *Constellations* 2,1 (1995): 114–40.

Dennett, Daniel. “The Moral First Aid Manual.” In *The Tanner Lectures on Human Values*. Vol.VIII. Salt Lake City: University of Utah Press, 1988.

Donnelly, Jack. *Universal Human Rights in Theory and Practice*. Ithaca: Cornell University Press, 2003.

Durkheim, Emile. *The Division of Labour in Society*. New York: Free Press, 1997.

Dworkin, Ronald. “Rights as Trumps.” In *Theories of Rights,* edited by Jeremy Waldron. New York: Oxford University Press, 1995.

Eide, Asbjørn. “Universalising Human Rights: the Process and Challenges in the Age of Globalisation.” In *Debates on Issues of Our Common Future,* edited by Wilhelm Krull. Göttingen: Velbrück Wissenschaft, 2000.

Erin, Charles A. “Who Owns Mo? Using historical entitlement theory to decide the ownership of human derived cell lines.” In *Ethics and Biotechnology*, edited by Anthony Dyson and John Harris. London, Routledge, 1994.

Etzioni, Amitai. *The Spirit of Community: Rights, Responsibilities and the Communitarian Agenda*. London: Fontana Press, 1995.

Feinberg, Joel. “The Nature and Value of Rights.” *The Journal of Value Inquiry* 4, 4 (1970): 227–257.

Feinberg, Joel. *Rights, Justice, and the Bounds of Liberty*. New Jersey: Princeton University Press, 1980.

Feinberg, Joel. *Social Philosophy*. New Jersey: Prentice Hall, 1973.

Fletcher, Joseph. “Give If It Helps But Not If It Hurts.” In *World Hunger and Moral Obligation*, edited by William Aiken and Hugh La Follette. New Jersey: Prentice-Hall, 1977.

Forst, Rainer. *Contexts of Justice. Political Philosophy beyond Liberalism and Communitarianism.* Berkeley: University of California Press, 2002.

Foucault, Michel. *Madness and Civilisation.* Translated by Richard Howard. London: Tavistock, 1975.

Foucault, Michel. *The Birth of the Clinic: An Archaeology of Medical Perception.* Translated by Alan Sheridan. London: Tavistock, 1976.

Gandhi, Mahatma. *Moral and Political Writings.* Vol.1. Edited by Raghavan Iyer. Oxford: Clarendon, 1986.

Gewirth, Alan. "Are there any absolute rights?" In *Theories of Rights,* edited by Jeremy Waldron. New York: Oxford University Press, 1995.

Habermas, Jürgen. *The Future of Human Nature.* Cambridge: Polity, 2003.

Halliday, Fred. "Human Rights in the Islamic Middle East." In *Politics and Human Rights*, edited by David Beetham. Oxford: Blackwell, 1995.

Hallowell, Nina. "Doing the Right Thing: genetic risk and responsibility." *Sociology of Health and Illness* 21, 5 (1999): 597–261.

Hardin, Garrett. "Lifeboat Ethics: The Case Against Helping the Poor." In *World Hunger and Moral Obligation*, edited by William Aiken and Hugh La Follette. New Jersey: Prentice-Hall, 1977.

Hart, H.L.A. "Are There Any Natural Rights?" In *Theories of Rights,* edited by Jeremy Waldron. New York: Oxford University Press, 1995.

Hart, H.L.A.. *The Concept of Law.* Oxford: Clarendon Press, 1961.

Häyry, Matti. "European Values in Bioethics: Why, What and How to Be Used?" *Theoretical Medicine* 24 (2003): 199–214.

Häyry, Matti. "Precaution and Solidarity." *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 199–206.

Hechter, Michael. *Principles of Group Solidarity.* Berkeley: University of California Press, 1987.

Hewitt, Martin. *Welfare and Human Nature. The Human Subject in Twentieth Century Social Politics.* New York: MacMillan, 2000.

Hobbes, Thomas. *Leviathan,* edited by Richard Tuck. Cambridge: Cambridge University Press, 1996.

Hohfeld, Wesley Newcomb. *Fundamental Legal Conceptions.* New Haven: Yale University Press, 1923.

Holm, Søren. "There is nothing special about genetic information." In *Genetic Information. Acquisition, Access, and Control*, edited by Alison Thompson and Ruth Chadwick. New York: Kluwer Academic/Plenum Publishers, 1999.

Holmes, Stephen, Cass R.Sunstein. *The Cost of Rights: Why Liberty Depends on Taxes.* New York: Norton, 1999.

Honoré, Anthony. "Property, Title and Redistribution." In *Applied Social and Political Philosophy*, edited by Elisabeth Smith and H. Gene Blocker. Englewood Cliffs: Prentice-Hall, 1994.

Houtepen, Rob, Ruud ter Meulen. "New Types of Solidarity in the European Welfare State." *Health Care Analysis* 8, (2000): 329–40.

Houtepen, Rob, Ruud ter Meulen. "Justice and Solidarity in Priority Setting in Health Care." *Health Care Analysis* 8 (2000): 327.

HUGO Ethics Committee. "Genetic Benefit-Sharing." *Science* 290, 5489 (2000): 49.

Hume, David. *A Treatise of Human Nature.* Oxford: Clarendon, 1978).

Hutcheson, Francis. *An Inquiry into the Origins of our Ideas of Beauty and Virtue.* Indianapolis: Liberty Fund, 2004.

Jasanoff, Sheila. *Designs on Nature. Science and Democracy in Europe and the United States.* Princeton: Princeton University Press, 2005.

Kant, Immanuel. "Groundwork of the metaphysics of morals." In *Practical Philosophy*. Translated and edited by Mary J. Gregor. New York: Cambridge University Press, 1996.

Kaveny, Cathleen M. "Jurisprudence and Genetics." *Theological Studies* 60, 1 (1999): 135.

Kerr, Anne. "Rights and Responsibilities in the Genetics Era." *Critical Social Policy* 23, 2 (2003): 208–226.

King, Jonathan. "Gene Patents Retard the Protection of Human Health." *GeneWatch* 10, 2–3 (1996): 10–11.

King, Patricia A. "The Past as Prologue: Race, Class, and Gene Discrimination" In *Gene Mapping. Using Law and Ethics as Guides,* edited by George J. Annas and Sherman Elias.New York: Oxford University Press, 1992.

Kitcher, Philip. *Science, Truth and Democracy*. Oxford: Oxford University Press, 2001.

Knoppers, Bartha M., Ruth Chadwick, Hiraku Takebe, Kåre Berg, Jose Maria Cantu, Abdallah S. Daar, Eva Marie Engels, Michael Kirby, Darryl Macer, Thomas H. Murray, Ren-Zong Qiu, Ishwar C. Verma and Dorothy C. Wertz. "HUGO urges genetic benefit-sharing." *Community Genetics* 3, 2 (2000): 88–92.

Korsgaard, Christine M. "Commentary on: G.A.Cohen: Equality of What? On Welfare, Goods and Capablilities." In *The Quality of Life*, edited by Martha Nussbaum and Amartya Sen. Oxford: Clarendon Press,1993.

Kymlicka, Will. *Liberalism, Community and Culture.* Oxford: Clarendon Press, 1989.

Laurie, Graeme, Kathryn G. Hunter. "Benefit-sharing and public trust in genetic research." In *Blood and Data. Ethical, Legal and Social Aspects of Human Genetic Databases,* edited by Gardar Árnason, Salvör Nordal and Vilhjálmur Árnason. Reykjavik: University of Iceland Press and the Centre for Ethics, 2004.

Le Grand, Julian. "Afterword." In *The Gift relationship: from human blood to social policy*. London: LSE Books, 1997.

Locke, John. "Second Treatise on Government." In *Two Treatises of Government*. Edited by Peter Laslett. Cambridge: Cambridge University Press, 1996.

MacDonald, Margaret. "Natural Rights." In *Theories of Rights,* edited by Jeremy Waldron. New York: Oxford University Press, 1995.

MacIntyre, Alasdair. "Moral Philosophy: What Next?" In *Revisions: Changing Perspectives in Moral Philosophy*, edited by Stanley Hauerwas and Alasdair MacIntyre. Notre Dame: University of Notre Dame, 1983.

MacIntyre, Alasdair. *After Virtue: A Study in Moral Theory.* London: Duckworth, 1981.

Mackie, J. L. "Can There be a Right-Based Moral Theory?" In *Theories of Rights,* edited by Jeremy Waldron. New York: Oxford University Press, 1995.

Macklin, Ruth. "The Ethics of Gene Patenting." In *Genetic Information. Acquisition, Access, and Control*, edited by Alison Thompson and Ruth Chadwick. New York: Kluwer Academic/Plenum Publishers, 1999.

Macklin, Ruth. *Double Standards in Medical Research in Developing Countries.* Cambridge: Cambridge University Press, 2004.

Magnus, David. “International Agricultural Perspectives on Benefit-Sharing“; available from http://www.bioethics.upenn.edu/prog/benefit/pdf/Magnus_David.pdf; accessed 1.03.2005.

Malinowski, Bronislaw. *Argonauts of the Western Pacific*. London: Routledge & Kegan Paul, 1972.

Mansur, Levi. “Gene Discovery, Ownership and Access for Developing Countries in the Era of Molecular Genetics.” *Electronic Journal of Biotechnology* 5, 1 (2002).

Marshall, T. H. *Citizenship and Social Class.* London: Pluto Press, 1992.

Mauss, Marcel. *The Gift. Forms and Functions of Exchange in Archaic Societies*. Translated by Ian Cunnison. New York: The Free Press, 1968.

McCloskey, H. J. “Rights.” *Philosophical Quarterly* 15 (1965): 115–127.

McCullough, Laurence B. “Justice and Health Care: Historical Perspectives and Precedents.” In *Justice and Health Care*, edited by E. E. Shelp. Boston: D.Reidel Publishing Company, 1981.

Meulen, Ruud. *Solidarity and Care in the European Union.* Final Report of a 4th FP project SolidCar. 2000.

Mill, John Stuart. *Utilitarianism.* New York: Prometheus Books, 1987.

Miller, David. “Justice and Global Inequality.” *Inequality, Globalisation and World Politics*, edited by Andrew Hurrell and Ngaire Woods. Oxford: Oxford University Press, 1999.

Miller, David. *Principles of Social Justice*. Cambridge: Harvard University Press, 1999.

Montgomery, Cal. “Critic of the Dawn.” *The Disability Rags. Ragged Edge Magazine Online* 2, 2001.

Murphy, Liam B. “Demands of Beneficence.” *Philosophy and Public Affairs* 22, 4 (1993): 267–292.

Narayan, Uma. *Dislocating Cultures: Identities, Traditions, and Third-World Feminism.* New York: Routledge 1997.

Narveson, Jan. *The Libertarian Idea.* Philadelphia: Temple University Press, 1988.

Nõmper, Ants. “Open Consent — A New Form of Informed Consent for Population Genetic Databases.” Ph.D.diss., University of Tartu, 2005.

Novas, Carlos, Nikolas Rose. “Genetic Risk and the Birth of the Somatic Individual.” *Economy and Society* 29, 4 (2000): 485–513.

Nozick, Robert. *Anarchy, State, Utopia.* Oxford: Blackwell, 1975.

Nussbaum, Martha, Amartya Sen. “Introduction.” *The Quality of Life*. Oxford: Clarendon Press, 1993.

Nussbaum, Martha. *Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy.* Cambridge: Cambridge University Press, 2001.

Nussbaum, Martha. *Women and Human Development. The Capabilities Approach.* New York: Cambridge University Press, 2000.

Ockham, William (of). *The Work of Ninety Days.* Translated and edited by John Kilcullen and John Scott. Lewiston: Edwin Mellen Press, 2001.

Okin, Susan Moller. *Justice, Gender and the Family.* New York: Basic Books, 1989.

O’Neill, Onora. *Faces of Hunger: An Essay on Poverty, Justice and Development.* London: Allen & Unwin, 1986.

de Ortúzar, María Graciela. “Towards a Universal Definition of ‘Benefit-Sharing’.” In *Populations and Genetics: Legal and Socio-Ethical Perspectives*, edited by Bartha M. Knoppers. Leiden: Martinus Nijhoff, 2003.

Ostergard, Robert L. Jr., Matthew Tubin, Jordan Altman. “Stealing from the Past: globalisation, strategic formation and the use of indigenous intellectual property in the biotechnology industry.” *Third World Quarterly* 22, 4 (2001): 643–656.

Otteson, James R. “Limits on Our Obligation to Give.” *Public Affairs Quarterly* 14, 3 (2000): 183–203.

Parfit, Derek. *Reasons and Persons.* New York: Oxford University Press, 1986.

Petchesky, Rosalind P. *Abortion and Woman’s Choice. The State, Sexuality and Reproductive Freedom.* London: Verso, 1986.

Plant, Raymond. “Why Social Justice?” In *Social Justice from Hume to Walzer*, edited by David Boucher, Paul Kelly and P.J. Kelly. London: Routledge 1998.

Pogge, Thomas. *World Poverty and Human Rights*. Cambridge: Polity Press, 2002.

Preis, Ann-Belinda S. “Human Rights as Cultural Practice: An Anthropological Critique.” *Human Rights Quarterly* 18, 2 (1996): 286–315.

Pufendorf, Samuel**.** *On the duty of man and citizen according to natural law*. Cambridge: Cambridge University Press, 2000.

Rawls, John. “Justice as Fairness: Political not Metaphysical.” *Philosophy and Public Affairs* 14, 3 (1985): 223–251.

Rawls, John. “The Priority of Right and the Ideas of the Good.” *Philosophy and Public Affairs* 17, 4 (1988): 251–276.

Rawls, John. *A Theory of Justice.* Cambridge: Harvard University Press, 1971.

Raz, Joseph. *The Morality of Freedom.* Oxford: Clarendon, 1988.

Resnik, David. *The Ethics of Science. An Introduction.* London: Routledge, 1998.

Resnik, David. “The Morality of Human Gene Patents.” *Kennedy Institute of Ethics Journal* 7, 1 (1997): 43–61.

Reynolds, Tom. “Gene Patent Race Speeds Ahead Amid Controversy, Concern.” *Journal of the National Cancer Institute* 92, 3 (2000): 184–186.

Robertson, Ann. “Biotechnology, Political Rationality and Discourses on Health Risk.” *Health* 5, 3 (2001): 293–309.

Robson, William. *Welfare state and welfare society: illusion and reality.* London: Allen &Unwin, 1976.

Rorty, Richard. “On Human Rights, Rationality and Sentimentality.” In *On Human Rights. The Oxford Amnesty Lectures 1993*, edited by Stephen Shute and Susan Hurley. New York: Basic Books, 1993.

Sandel, Michael. *Liberalism and the Limits of Justice.* Cambridge: Cambridge University Press, 1982.

Scanlon, Thomas. “Value, Desire, and Quality of Life.” In *The Quality of Life*, edited by Martha Nussbaum and Amartya Sen. Oxford: Clarendon Press, 1993.

Scheffler, Samuel. “Natural Rights, Equality, and the Minimal State.” In *Reading Nozick. Essays on ‘Anarchy, State, and Utopia’*, edited by Jeffrey Paul. New Jersey: Rowman and Littlefield, 1981.

Schrecker, Ted. “Benefit-Sharing in the New Genomic Marketplace: Expanding the Ethical Frame of Reference.” In *Populations and Genetics: Legal and Socio-Ethical Perspectives*, edited by Bartha M. Knoppers. Leiden: Martinus Nijhoff, 2003.

Schwefel, Detlef. “International Health in Globalised Development Perspective.” *Journal of Public Health* 12 (2004): 177–184.

Sen, Amartya, Bernard Williams, eds. *Utilitarianism and Beyond.* London: Cambridge University Press, 1982.

Sen, Amartya. “Human Rights and Asian Values.” *The New Republic* 1997, 14 & 21.

Sen, Amartya. “Justice: Means versus freedoms.” *Philosophy and Public Affairs* 19, 2 (1990): 111–121.

Sen, Amartya. *Poverty and Famines: An Essay on Entitlement and Deprivation.* Oxford, Clarendon Press, 1981.

Sen, Amartya.“Capability and Well-Being.” In *The Quality of Life*, edited by Martha Nussbaum and Amartya Sen. Oxford: Clarendon Press,1993.

Shaftesbury, Anthony A.C. (3rd Earl of). *Characteristics of men, manners, opinions, times*, edited by Lawrence E. Klein. Cambridge: Cambridge University Press, 1999.

Shildrick, Margrit. *Leaky Bodies and Boundaries. Feminism, Postmodernism and (Bio)ethics.* London: Routledge, 1997.

Sidgwick, Henry. *Methods of Ethics.* Indianapolis: Hackett, 1982.

Simm, Kadri. “Benefit-Sharing and Population Biobanks.” In *Ethics and Governance of Human Population Databases*, edited by Vilhjalmur Árnason, Gardar Árnason, Ruth Chadwick and Matti Häyry. Cambridge: Cambridge University Press, 2006 (forthcoming).

Simm, Kadri. “Benefit-sharing: an inquiry regarding the meaning and limits of the concept in human genetic research.” *Genomics, Society and Policy* 1,2 (2005): 29–40.

Simmel, Georg. “How is Society Possible?” *American Journal of Sociology* 16 (1910–1911): 372–391.

Singer, Peter. “Famine, Affluence, and Morality.” *Philosophy and Public Affairs* 1, 3 (1972): 229–243.

Singer, Peter. *Practical Ethics.* New York: Cambridge University Press, 1993.

Slote, Michael A. “The Morality of Wealth.” In *World Hunger and Moral Obligation,* edited by William Aiken and Hugh La Follette. New Jersey: Prentice-Hall, 1977.

Smith, Adam. *Theory of Moral Sentiments.* Cambridge: Cambridge University Press, 2002.

Strauss, Leo. ”Mis on poliitiline filosoofia?” In *Kaasaegne poliitiline filosoofia,* edited by Jüri Lipping. Tartu: EYS Veljesto Kirjastus, 2002.

Takala, Tuija. “Justice for All? The Scandinavian Approach,” in *Medicine and Social Justice: Essays on the Distribution of Health Care*, edited by Rosamond Rhodes, M. Pabst Battin and Anita Silvers. New York: Oxford University Press, 2002.

Taylor, Charles. “The diversity of goods.” In *Utilitarianism and Beyond,* edited by Amartya Sen and Bernard Williams. London: Cambridge University Press, 1982.

Taylor, Charles. *Sources of the Self. The Making of the Modern Identity.* Cambridge: Cambridge University Press, 1989.

Thomson, Judith Jarvis. “Some Ruminations on Rights.” In *Reading Nozick. Essays on ‘Anarchy, State, and Utopia’,* edited by Jeffrey Paul. New Jersey: Rowman and Littlefield, 1981.

Titmuss, Richard. *The Gift Relationship: from human blood to social policy.* London: LSE Books, 1997.

Tönnies, Ferdinand. *Community and Society.* East Lansing: Michigan State University Press, 1957.

Tooley, Michael. “Abortion and Infanticide.” *Philosophy & Public Affairs* 2, 1 (1972): 37–65.

Townend, David. “Who owns genetic information?” In *Society and Genetic Information, Codes and Laws in the Genetic Era*, edited by Judit Sandor, Budapest: Central European University Press, 2003.

Trappenburg, Margo. “Lifestyle Solidarity in the Healthcare System.” *Health Care Analysis* 8 (2000): 65–75.

Turner, Bryan. “Outline of a Theory of Human Rights.” *Sociology* 27, 3 (1993): 489–512.

Turner, Bryan, Chris Rojek. *Society and Culture. Principles of Scarcity and Solidarity.* London: Sage Publications, 2001.

Unger, Peter. *Living High and Letting Die: Our Illusion of Innocence.* New York: Oxford University Press, 1996.

Vlastos, Gregory. “Justice and Equality.” In *Theories of Rights,* edited by Jeremy Waldron. New York: Oxford University Press, 1995.

Waldron, Jeremy. “Superseding Historic Injustice.” *Ethics* 103, 1 (1992): 4–28.

Walzer, Michael. *Spheres of Justice: A Defense of Pluralism and Equality.* Oxford: Blackwell, 1985.

Weber, Max. *Economy and Society: An Outline of Interpretive Sociology.* Translated and edited by Günther Roth and Claus Wittich. Berkeley: University of California Press, 1978.

Weijer, C. “Benefit-sharing and other protections for communities in genetic research.” *Clinical Genetics* 58 (2000): 367–368.

Wellman, Carl. *The Proliferation of Rights. Moral Progress or Empty Rhetoric?* Boulder: Westview Press, 1999.

Williams, Garrath, Doris Schroeder. “Human genetic banking: altruism, benefit and consent.“ *New Genetics and Society* 23, 1(2004): 89–10.

National and international legal documents and policy papers

United Nations and Its Organisations

Ad-Hoc Open-Ended Working Group on Access and Benefit-Sharing, *Conference of the Parties to the Convention on Biological Diversity*, 2004; available from http://www.biodiv.org/doc/meetings/cop/cop-07/official/cop-07-06-en.pdf; accessed 14.03.2005.

United Nations Economic and Social Council, *The right to the highest attainable standard of health. General Comment No. 14, 2000: available from http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En?OpenDocument; accessed 16.08.2005.*

United Nations Secretariat of the Convention on Biological Diversity, *Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilisation*, 2002; available from http://www.biodiv.org/doc/publications/cbd-bonn-gdls-en.pdf; accessed 28.08.2005.

Join United Nations Programme on HIV/AIDS (UNAIDS), *Ethical considerations in HIV/AIDS preventive vaccines research*, 2004; available from http://www.unaids.org/html/pub/publications/irc-pub01/jc072-ethicalcons_en_pdf.pdf; accessed 15.08.2005.

United Nations Educational, Scientific and Cultural Organization (UNESCO), *Declaration on the Human Genome and Human Rights*, 1997; available from http://portal.unesco.org/en/ev.php-

URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html; accessed 15.08.2005.

United Nations, *Convention on Biological Diversity* (CBD), 1992; available from http://www.biodiv.org/convention/articles.asp; accessed 14.03.2005.

United Nations Development Programme, *Human Development Report,* 2003; available from http://www.undp.org/hdr2003/; accessed 15.01.2005.

United Nations International Covenant on Economic, Social and Cultural Rights; available from *http://www.unhchr.ch/html/menu3/b/a_cescr.htm*; accessed 14.03.2005.

Human Genome Organisation

HUGO ELSI-Committee, *Statement on the Principled Conduct of Genetic Research*, 1995; available from http://www.gene.ucl.ac.uk/hugo/conduct.htm; accessed 15.08.2005.

HUGO Ethics Committee, *Statement on Benefit-Sharing*, 2000; available from http://www.gene.ucl.ac.uk/hugo/benefit.html; accessed 14.03.2005.

HUGO, *Mission Statement,* available from http://www.gene.ucl.ac.uk/hugo/mission.htm; accessed 14.03.2005.

HUGO, *Statement on Human Genomic Databases*, 2002; available from http://www.gene.ucl.ac.uk/hugo/HEC_Dec02.html; accessed 23.08.2005.

HUGO, *Statement on the Patenting of DNA Sequences*, 1995; available from http://www.gene.ucl.ac.uk/hugo/patent; accessed 23.08.2005.

Other

American Medical Association (AMA), homepage available from http://www.ama-assn.org/ama/pub/category/13570.html; accessed 23.08.2005.

Brazilian National Health Council, *Resolution 196/96 — On Research Involving Human Subjects*, 1996; available from http://www.aids.gov.br/resolution_196.htm; accessed 17.08.2005.

Council for International Organisations of Medical Sciences (CIOMS), *International Ethical Guidelines for Biomedical Research Involving Human Subjects,* 2002; available from http://www.cioms.ch/guidelines_nov_2002_blurb.htm ;accessed 23.08.2005. Guideline 10.

Council of Europe, *European Social Charter*, 1961; available from http://www.coe.int/T/E/Human_Rights/Esc/;accessed 13.05.2005.

Estonian Human Genes Research Act, available from http://www.geenivaramu.ee/index.php?lang=eng&sub=18&eetika=1; accessed 29.08.2005.

European Commission, *Communication On the Precautionary Principle*, 2000; available from http://europa.eu.int/comm/dgs/health_consumer/library/pub/pub07_en.pdf; accessed 17.08.2005.

European Commission, *Directive on Clinical Trials 2001/20/EC,* 2001; available from http://eudract.emea.eu.int/docs/Dir2001-20_en.pdf; accessed 12.08.2005.

European Group on Ethics in Science and New Technologies, *Ethcal Aspects of Clinical Research in Developing Countries*, 2003; available from http://www.europa.eu.int/comm/european_group_ethics/docs/avis17_en.pdf; accessed 26.08.2005.

Global Forum for Health Research, *The 10/90 Report on Health Research,* 2000; available from http://www.globalforumhealth.org/Site/002__What%20we%20do/005__Publications/001__10%2090%20reports.php; accessed 28.08.2005.

Nuffield Council on Bioethics, *The Ethics of Research Related to Health Care in Developing Countries*, 2002; available from http://www.nuffieldbioethics.org/publications/pp_0000000013.asp; accessed 25.08.2005.

United States National Bioethics Advisory Commission (NBAC), *Ethical and Policy issues in International Research: Clinical Trials in Developing Countries,* 2001; available from http://bioethicsprint.bioethics.gov/reports/past_commissions/nbac_international.pdf; accessed 26.08.2005.

World Health Organisation, *Constitution*, 1946; available from http://w3.whosea.org/LinkFiles/About_SEARO_const.pdf; accessed 12.05.2005.

World Health Organisation (WHO), *Genomics and World Health*, 2002; available from http://whqlibdoc.who.int/hq/2002/a74580.pdf; accessed 12.01.2005.

World Medical Association (WMA), *Helsinki Declaration,* 2002; available from http://www.wma.net/e/policy/b3.htm; accessed 23.08.2005.

World Trade Organisation (WTO), *What are Intellectual Property Rights?* available from http://www.wto.org/english/tratop_e/trips_e/intel1_e.htm; accessed 23.08.2005.

SUMMARY IN ESTONIAN

Uurimus hüvedejagamise põhjendamisest

Käesolev töö keskendub hüvedejagamise mõiste analüüsile ja vaatleb selle eri põhjendamisviise. Hüvedejagamist (ingl.k. *benefit-sharing*) on viimastel aastakümnetel rõhutatud kui olulist moraalset põhimõtet eelkõige inimgeeniuuringute korraldamisel. Kuid samas on seda printsiipi hakatud üha olulisemaks pidama ka väljaspool meditsiinisfääri ning nägema põhjusi selle rakendamiseks globaalse õigluse raamistikus. Hüvedejagamine sisaldab endas tegelikult nii hüvede kui ka koormiste jagunemist teadusuuringute ajal ning samuti järgneva perioodi jooksul: mida n-ö võlgnetakse inimestele, kes on osalenud teadusuuringutes ning samuti kogukondadele, kes on andnud oma panuse ravimi või tehnoloogia arengusse. Ent ehkki hüvedejagamine on vähemalt retoorikas rahvusvaheliselt tunnustatud põhimõte, pole kuigi palju tegeldud selle printsiibi sisulise põhjendamise ega süstemaatilise uurimisega.

Käesolev töö kuulub praktilise filosoofia valdkonda ning kõige enam leiavad siin tarvitust moraali-ja poliitikafilosoofiast pärinevad argumendid. Neid argumente rakendatakse hüvedejagamise kui tänapäeval eelkõige biomeditsiinis olulise mõiste analüüsil. Samas püüab käesolev töö viidata olulistele seostele seni suhteliselt kitsa rakendusega hüvedejagamise põhimõtte ning õigluse küsimuse vahel, mis on märksa laiem ning filosoofia ajaloos üsna kesksel kohal. Nii lõikubki hüvedejagamine biomeditsiinis tegelikult järjest enam sotsiaalse (ning ka globaalse) õigluse küsimustega, mis tegelevad ju samuti hüvede ning koormiste jagunemise problemaatikaga.

Ent kuigi argumentatsioon töös pärineb praktilisest filosoofiast, ei ole tegemist distsipliinipõhise ega ühe teooria keskse, vaid pigem probleemipõhise uurimusega. Eesmärgiks on olnud kasutada filosoofia rikkalikke võimalusi hüvedejagamise mõiste täpsustamiseks ja analüüsiks ning erinevad filosoofilised mõisted ja teooriad on siinkohal olnud vahendiks probleemi uurimisel. Kuna teema ise on aga interdistsiplinaarne, olen pidanud oluliseks hõlmata asjakohast teadmist ka bioeetikast, meditsiiniantropoloogiast ning arenguuuringutest (*development studies).* Töö on jagatud nelja ossa. Esimeses osas tegelen hüvedejagamise ajaloolis-kontseptuaalse analüüsiga ning kolmes järgmises võtan süstemaatiliselt eraldi vaatluse alla kolm võimalikku põhjendusviisi. Uurin ka argumente hüvedejagamise vastu.

Esimeses peatükis annan alustuseks ülevaate hüvedejagamise põhimõtte kajastusest rahvusvahelistes regulatsioonides ning eriti mitmesugustes meditsiinivaldkonna dokumentides. Meditsiinis on hüvedejagamist enamasti põhjendatud riskipõhiselt (osalejad võtavad vabatahtlikult riske) ning lähtuvalt mittekahjustamise ning heasoovlikkuse printsiipidest (*non-maleficence* ja *benevolence*). Hüvedejagamine on traditsioonilises meditsiinikontekstis olnud enamasti kompensatsioonipõhine ning olulisel määral on lähtutud inimeste vajadustest (*needs*). Teadusuuringud looma-ja taimegeneetikas on aga kaasa toonud võimaluse ja vajaduse hüvedejagamise teistsuguseks põhjendamiseks. Nimelt kasutatakse uuringute käigus palju ressursse, mille suhtes kohalikul elanikkonnal võib kehtida omandiõigus. Seda laadi kollektiivne osalus hüvedejagamises erineb aga meditsiinivaldkonna indiviidikesksest praktikast. Nüüdseks on kollektiivse jagamise ideed hakatud hindama ka biomeditsiinis, iseäranis suuremate rahvastikupõhiste ning geneetikaga seotud projektide puhul.

Kuigi omandiõigusel põhinev hüvedejagamine on inimgeneetikas veel üsna harv nähtus, on see siiski järjekordne näide teadusuuringute jätkuvast kommertsialiseerumisest, kus ümberjagava õigluse aluspõhimõtteks on saamas teeneprintsiip (*desert*). See on tekitanud valuliku reaktsiooni rahvusvahelises üldsuses, sest seni on meditsiiniga seotud eluvaldkondades olulisemaks peetud vajadusepõhist lähenemist ning mitmesuguseid meditsiinieetika printsiipe. Samas on selge, et laiahaardelisemat hüvedejagamist ei saa enam õigustada ka ainult traditsiooniliste meditsiiniuuringutes kehtinud põhimõtetega, sest need piiritlesid hüvedejagamist, lähtudes uuringutesse kaasatuse põhimõttest. Kuid kas või juba tänapäeval nii populaarsete rahvastikupõhiste geeniandmebaaside puhul on väga raske tõmmata tavapärast eraldusjoont projektis osalejate ja mitteosalejate vahele. Geneetiline info on oma olemuselt jagatud, seega võivad uuringud kaasa tuua riske ka neile, kes formaalselt projektis ei osale. Kahtluse alla on seatud niisugused traditsioonilised arstiteaduse ning meditsiiniõiguse kategooriad nagu privaatsus ning vaid konkreetset patsienti puutuva info eraldamise võimalikkus. Järjest enam arutletakse kogukonna ning elanikkonna põhjendatud kaasamise üle hüvedejagamisse.

Oma töös väidan, et hüvedejagamise kontseptsiooni puhul on vajalik piiritleda kahte tasandit. Hüvedejagamise põhjendamisel on oluline eristada konkreetsete teadusprojektidega seotud õigluseküsimusi ning teiseks probleeme, mis kaasnevad teadus- ja tehnoloogiaarengu saavutuste jätkuvalt ebavõrdse kättesaadavusega kogu maailmas (*specific* ja *universal benefit-sharing)*. Hüvedejagamise senine retoorika ning põhjendusmudelid pärinevad enamasti meditsiinieetikast ning omandiõiguste-keskse õigustusega põllumajandusuuringutest, kuid järjest enam on püütud seda mõistet rakendada globaalse ebaõigluse kontekstis, kus teadusuuringute tulemusena saavutatu jääb liigagi paljudele kättesaamatuks. Ühtlasi suhestub diskussioon hüvedejagamise üle üha enam poliitilise ja majandusliku ebavõrdsusega ning samuti võimuküsimustega maailmas. Kuivõrd edukalt aga saab konkreetsete teadusprojektide kontekstis toimivaid põhjendusmudeleid üle kanda universaalsesse konteksti?

Mõttekäik universaalsest hüvedejagamisest ei ole pelgalt reaktsioon teadusmaailma kommertsialiseerumisele (näiteks on farmaatsiaettevõtted tänapäeval maailmas ühed kõige kasumlikumad), vaid püüab tõstatada küsimusi, mis seostuvad teadus-ja tehnoloogiaarengu tulemuste kättesaadavusega (õigemini kättesaamatusega), kogu inimkonna seisukohast. Näiteks on vajalikud ravimid kalli hinna tõttu kättesaamatud suuremale osale maailma elanikkonnast; samuti valitakse meditsiiniuuringute prioriteedid eelkõige rikka, n-ö lääneriikide elanikkonna huvidest lähtudes — see aga tähendab, et 90% meditsiiniuuringute rahast maailmas investeeritakse projektidesse, mis tegelevad kõigest 10% maailma elanikkonna terviseprobleemidega. Biomeditsiin on näide valdkonnast, kus traditsioonilised õiglusprintsiibid on jäänud uute ärikesksete koosluste pealetungi all järjest jõuetumaks. Hüvedejagamise põhimõte on üks võimalus selliste tendentsidega kriitiliselt suhestuda.

Üleilmastumine on sageli kaasa toonud selle, et arengumaade elanikud võtavad teadusuuringutes osaledes enda kanda riske, kuid tulemuste tähtsus neile endile on väike või puudub hoopiski. Nii ei saa hüvedejagamist sedavõrd universaalses kontekstis põhjendada meditsiinieetika normidega ega omandiargumentidega (kuigi näiteks inimgenoomi on sümboolselt nimetatud kogu inimkonna pärandiks). Pigem on universaalse hüvedejagamise kontseptsioon keerukas kompleks nii neist varasematest rakendustest kui ka teistest, humanistlikest põhimõtetest, mis keskenduvad võrdsusideaalile ning vajadusprintsiibile ümberjagava õigluse kontekstis.

Töö ülejäänud kolmes osas analüüsingi võimalikke põhjendusmudeleid, mis võiksid olla olulised ja asjakohased eelkõige universaalse hüvedejagamise tasandil. Keskendumise solidaarsusprintsiibile ning õigustekeskse argumentatsioonile on tinginud järeldus, et just neid lähenemisviise on hüvedejagamise retoorilisel põhjendamisel enim rakendatud. Järelikult on mõiste analüüsil oluline käsitleda ning hinnata just nende argumentide sobivust ka preskriptiivses/ettekirjutavas võtmes. Kuigi konsekventsialistlikku põhjendamismudelit pole biomeditsiinilise hüvedejagamise puhul palju analüüsitud, on selle üle siiski arutletud veidi teises, kuid paljuski sarnases, nimelt näljahädade kontekstis. Hüvedejagamise konsekventsialistlik põhjendamine, olgu hüvedeks ligipääs elutähtsatele ravimitele või hoopis toidule, on argumentsioon, mille asjakohasuse analüüsimine on vajalik, hoolimata sellest, et meditsiinivaldkonna retoorika tänapäeval eelistab pigem mitte-konsekventsialistlikke diskursusi. Samas pole ma oma töös seadnud eesmärki välistada võimalikke teistsuguseid põhjendusviise hüvedejagamisele.

Teine peatükk keskendub solidaarsuse mõiste analüüsile, mille olulisust on rõhutatud just eelkõige sellega seoses, et solidaarsus võimaldab hüvedejagamist põhjendatult laiendada väljapoole kompensatsioonil või teenel põhinevaid õiglusmudeleid. Samas on solidaarsus siiski üsna ähmane mõiste. Poliitilises filosoofias seostub solidaarsus eelkõige kommunitaristlike mõttevooludega, kuid tegelikult on sel mõistel oluline koht ka liberaalses kontraktualismis ning heatahtlikkusel ning heategevusel põhinevates diskursustes. Analüüsin solidaarsuse mõistet kolmest aspektist. Esiteks rõhutan nii ratsionaalsuse kui emotsioonide olulisust solidaarsusmotivatsioonis, seda nii instrumentaalses mõttes kui seesmiselt (st tunnustades mõlema moraalset väärtust). Teiseks, solidaarsus kätkeb endas teatavat dihhotoomiat: enamasti ollakse kellegagi solidaarne, ühtaegu välistades sellega solidaarne olemise kellegi teisega. Nii et kas solidaarsus saab üldse olla mõistena asjakohane globaalsel tasandil — kui kedagi välja jätta justkui ei saaks ega tohikski? Siiski väidan, et üleilmastumine on protsess, mis inimkonda üha enam ühte seob ning rõhutab kõigi teatavat vastastikust sõltuvust, mille raames solidaarsus on võimalik. Lõpuks käsitlen solidaarsuse ning õigluse mõiste teatavat kattumist ning jõuan järeldusele, et niisugune komplementaarsus on universaalsel hüvedejagamise tasandil vaid tervitatav.

Kolmas peatükk analüüsib konsekventsialistlikku argumenti hüvedejagamise põhjendusena. Keskseks on Peter Singeri negatiivse konsekventsialismi argument halva vältimise kohta (*avoiding harm*), mille globaalse asjakohasuse üle käis aktiivne arutelu 1970.–1980. aastatel seoses Aafrika näljahädadega. Kuigi halva vältimise printsiip on intuitiivselt köitev, tekivad probleemid selle rakendamisel, kuna printsiip (vähemalt selle singerlikus tõlgenduses) osutub ülinõudlikuks. Kui meie moraalne kohus on halba vältida, siis oleme põhimõtteliselt alati positsioonil, kus seda on võimalik ja tulebki teha (sest alati on maailmas midagi halba toimumas ja peaaegu alati saaksime selle suhtes midagi ka ette võtta). Traditsiooniliselt on kõnealust printsiipi piiratud kohuse ja heategevuse põhimõttelise eristamise teel. Selline eristus toetub aga enamasti õiguste-keelele, mida konsekventsialistlik mõtteviis ei tunnusta. Kokkuvõttes väidan, et konsekventsialistlik argument universaalsel hüvedejagamise tasandil vajab tõhusaks toimimiseks kitsendusi, ning arutlen võimalike piiramismehanismide üle.

Neljandas peatükis vaatlen õiguste-diskursuse rakendatavust. Kõigepealt annan lühiülevaate õiguste filosoofilisest ajaloost. Ma ei väida, et eksisteerib õigus hüvedejagamisele, kuid näitan siiski, et õiguste-diskursust saab selles protsessis rakendada. Näitena käsitlen õigust tervishoiuteenustele (*right to health care)*. Tervishoiule keskendumine on siinkohal põhjendatud, kuna niihästi biomeditsiinis laiemalt kui inimgeneetikas kitsamalt seostuvad võimalikud jagatavad hüved eelkõige tervise ning heaoluga. Ja et selle õiguse näol on tegemist positiivse õigusega, mida näiteks libertaarne poliitiline filosoofia ei tunnusta, siis analüüsin ka positiivsete õiguste vastast argumentatsiooni (põhiliselt R. Nozickule toetudes). Väidan, et ei ajaloolised, pragmaatilised ega moraalsed argumendid positiivsete õiguste vastu ei pea paika, ning jõuan järeldusele, et positiivsed õigused on filosoofiliselt põhjendatud kategooria (ja seda isegi libertaarsetest alustest lähtudes). Järgnevalt keskendungi võimalustele põhjendada õigust tervishoiuteenusele. Selleks kasutan Norman Danielsi õiglase tervishoiu teooriat ning Amartya Sen'i ja Martha Nussbaumi võimete- ning funktsionaalsuste-keskset lähenemisviisi (*capabilities/functionings account*). Vastates nende lähenemisviiside kriitikale, põhjendan õigust tervishoiuteenusele ning selle olulisust inimõiguste diskursuses ning hüvedejagamise õigustamisel.

Kuna hüvedejagamine on kompleksne mõiste ja nähtus, siis ei välista ühe põhjendusmudeli kasutamine veel automaatselt teist. Vaatamata erinevustele rõhuasetustes ja selgitustes on neil lähenemisviisidel ka palju ühist, eriti mis puudutab moraali nimel esitatud väidete paljuski kattuvat aluspõhja. Omal moel on kõigi nende teoreetiliste käsitluste lähtepunktiks inimese kui sellise olukord *(human condition)* — tema vajadused, väärtused, võimed, haavatavus — ja selle olukorra moraalse olulisuse tunnustamine.

Käesolev töö on ennekõike püüdnud filosoofiliselt põhjendada hüvedejagamise ideed ning pakkuda välja argumente selle ajalooliselt võrdlemisi piiratud raamistiku palju laialdasema (ehk globaalse) rakendamise õigustamiseks. Kunagi põllumajandusest ning meditsiiniuuringutest alguse saanud hüvedejagamine on oma algsetest põhjendusmudelitest välja kasvanud ja vajab globaalse õiglusprobleemistiku kontekstis sobivamaid argumente. On oluline liikuda bioeetika suhteliselt indiviidikesksest diskursusest väljapoole ning kaasata poliitilisi argumente (sealhulgas õiguste-keelt), mis oleksid rakendatavad globaalses kontekstis ning võimaldaksid pakkuda vastukaalu majanduskesksele (ehk kasumile orienteeritud) paradigmale biotehnoloogias. Samuti tuleks hüvedejagamise mõistet rakendada rahvusvahelises teaduspoliitikas, eriti mis puudutab uuringuprioriteetide seadmist.

ACKNOWLEDGEMENTS

This thesis is very much related to (or actually has grown out of) the research project that I was involved with for 3 years, namely the EU funded ELSAGEN (Ethical, Legal and Social Aspects of Human Genetic Databases). While my initial interest at the beginning of my doctoral studies concerned social justice issues, especially pertaining to health care, then work within ELSAGEN directed my focus towards a more specific topic of benefit-sharing. Besides the European Commission funding I am also grateful to Volkswagen Stiftung, Open Estonia Foundation, Nordic Academy for Advanced Studies, Kristjan Jaak and Herbert Quandt Förderprogramm at the University of Konstanz for financial support during doctoral studies.

But of course, all the money in the world would not amount to much if it was not for my colleagues and friends who have supported me throughout. Professor Margit Sutrop has been an unbounded source for support and encouragement through many years, her energy, resolve and insights simply inestimable. Dr. Tuija Takala’s help with the thesis has been invaluable and her sharp mind has much strengthened and refined my work.

I am indebted to Dr. Graham Lewis who provided substantial comments on large part of the thesis. I am also grateful to Professor Matti Häyry for comments on part of the thesis.

I would like to thank my friends and colleagues from Tartu, Tallinn, Budapest, York and Helsinki who have provided support and inspiration for years throughout my studies.

I am of course indebted to my family in unaccountable ways. My final thanks go to Rene for love and encouragement.

CURRICULUM VITAE

General Data

Name: Kadri Simm
Date and place of birth: April 30th, 1976, Kiviõli, Estonia
Nationality: Estonian
Contact information: Department of Philosophy, University of Tartu
Lossi 3–234, Tartu 50090
Phone: +372 737 5327, kadri@eenet.ee

Education

1994–2000	University of Tartu, Department of History (BA)
2000–2001	Central European University, Budapest, Department of Gender Studies (MA)
2001–	University of Tartu, Department of Philosophy (PhD student)
August 2002	University of Oslo, Oslo Summer School in Comparative Social Sciences
Sept–Oct 2003	University of Konstanz, visiting student
Sept–Dec 2004	University of York, Marie Curie fellow
Jan–June 2004	University of Helsinki, visiting student

Professional experience

From 2001	researcher, lecturer and project manager at University of Tartu, Department of Philosophy and Centre for Ethics

Academic activities

Main research interests: moral and political philosophy, bioethics, feminist philosophy

CURRICULUM VITAE

Üldandmed

Nimi: Kadri Simm
Sünniaeg ja -koht: 30.04.1976, Kiviõli
Kodakondsus: Eesti
Kontaktandmed: Filosoofia osakond, Tartu Ülikool
Lossi 3–234, Tartu 50090
Tel: +372 737 5327, kadri@eenet.ee

Haridus

1994–2000	Tartu Ülikool, ajalugu (BA)
2000–2001	Kesk-Euroopa Ülikool, Budapest, soo-uuringud (MA)
2001–	Tartu Ülikool, filosoofia (doktorantuur)
august 2002	Oslo Ülikool, Oslo suveülikool võrdlevas sotsiaalteaduses
sept–okt 2003	Konstanzi ülikool, doktorant
sept–dets 2004	York'i ülikool, Marie Curie teadur
jan–juuni 2004	Helsinki ülikool, doktorant

Erialane töökogemus

Alates 2001	teadur, õppejõud ja projektijuht Tartu Ülikoolis, filosoofia osakonnas ja Eetikakeskuses

Peamised uurimisvaldkonnad

Moraali- ja poliitikafilosoofia, bioeetika, feministlik filosoofia

LIST OF RELEVANT PUBLICATIONS

Peer-reviewed articles in journals or edited books:

- Simm, Kadri. “Benefit-sharing: an inquiry regarding the meaning and limits of the concept in human genetic research.” *Genomics, Society and Policy* 1,2 (2005): 29–40.
- Simm, Kadri. “Benefit-Sharing and Population Biobanks.” In *Ethics and Governance of Human Population Databases*, edited by Vilhjalmur Árnason, Gardar Árnason, Ruth Chadwick and Matti Häyry. Cambridge: Cambridge University Press, 2006 (forthcoming).
- Simm, Kadri (with M. Sutrop). “The Estonian health care system and the genetic database project: from limited resources to big hopes.” *Cambridge Quarterly on Health Care Ethics* 13, 3 (2004): 254–262.
- Simm, Kadri. "The contested site of human nature. Applying 'trace' to the Strategic Action Plan of the Estonian Ministry of Social Affairs 2000–2010." In *The Heart of the Matter. The Contribution of the Ethic of Care to Social Policy in Some New EU Member States,* edited by Selma Sevenhuijsen and Alenka Svab. Ljubljana: Peace Institute, 2004.
- Simm, Kadri. “Exercises in value and argumentation.” In *How to best teach bioethics*, edited by Jon Elster and Helena von Troil. Copenhagen: Nordic Council of Ministers, 2004.
- Simm, Kadri. “Inimõigustest kriitilise pilguga.” *Ariadne Lõng* 2, (2002): 166–173.