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Report of the IBC on the Principle of Non-discrimination and Non-stigmatization

The International Bioethics Committee (IBC) started reflecting on the Principle of Non-Discrimination and Non-Stigmatization as set forth in Article 11 of the Universal Declaration on Bioethics and Human Rights prior and during its 19th Session (Paris, September 2012) as part of its 2012-2013 work programme. This Report was presented for consideration and discussion during the 20th Session of the IBC in Seoul, Republic of Korea (19-21 June 2013) and was finalized taking into consideration the observations and comments proposed by the Intergovernmental Bioethics Committee (IGBC) during its 8th Session in UNESCO Headquarters, Paris (5-6 September 2013).

It does not pretend to be exhaustive nor prescriptive and does not necessarily represent the views of the Member States of UNESCO.

REPORT OF THE IBC ON THE PRINCIPLE OF NON-DISCRIMINATION AND NON-STIGMATIZATION

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EXECUTIVE SUMMARY

In October 2005 the Universal Declaration on Bioethics and Human Rights (UDBHR) was adopted by the General Conference of UNESCO. In this report, the International Bioethics Committee (IBC) turns its attention to Article 11 of the Declaration, which pertains to Non-Discrimination and Non-Stigmatization. This article provides that:

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

The IBC believes that there is room for clarification of the scope, meaning and application of this principle. This report explains the meaning of the central terms – discrimination and stigmatization – and finally applies the principle to six contextual examples originating in domains related to medicine, life sciences and associated technologies as applied to human beings. They serve to illustrate some of the diverse situations where discrimination and stigmatization may occur in everyday life in modern societies.

Article 11 is firmly rooted in international human rights law and the scope of the article is determined by the scope of the Declaration itself. Thus Article 11 applies to ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, political, legal and environmental dimensions. From the wording of the principle one can deduce that only those distinctions that impair human dignity, human rights or fundamental freedoms are rightfully called discriminatory under Article 11. A decision or a practice that is discriminatory is one that infringes upon these fundamental notions and such decisions or practices are objectionable. Article 11 provides no list of grounds for discrimination or stigmatization. Indeed it explicitly states that discrimination or stigmatization on any ground is forbidden. Examples of characteristics that should not be grounds for special disqualifications, harms and restrictions are sex, race, religion, political belief, national origin or sexual orientation.

In contrast to discrimination, stigmatization is more of a social concern than a legal concept. In its more common meaning, a stigma is a mark of shame, disgrace or discredit. To impose a stigma upon a person is to render that person easier to treat with disrespect. The stimuli for the use of labels of this sort are various but fear and ignorance are the most prominent. In times of economic depression or shortage of resources where one's own interests are threatened, or in times of turmoil when in search for a scapegoat to explain the sufferings, it is not uncommon for these prejudices to color one's judgment and influence one's actions.

There is no definitive list of discriminatory or stigmatizing practices. Some practices are clearly discriminatory and need no comment. The only thing needed in those cases is action: naming, shaming, prevention, and punishing, i.e. legal intervention. In other cases, however, the risks of discrimination or stigmatization are not so clearly discernible.

The IBC has therefore decided to examine a number of contextual examples in order to identify possible risks for discrimination or stigmatization, foster awareness and give specific recommendations for policy-makers. Generally speaking, poverty, racism and sexism are examples of persistent problems for societies. In the context of modern medicine and science, persistent problems that involve discrimination and stigmatization, assessed in this report, are access to medications for neglected diseases, HIV/AIDS with the burden of stigmatization that it

still carries, and organ donation, transplantation and trafficking. As persistent problems, they are unfortunately familiar, although they have evolved in certain aspects. There are also emerging scientific and technological developments that could aggravate persistent problems or even create new versions of these problems, however admirable and valuable these scientific and technological developments might otherwise be. In this light biobanks, nanotechnology, and neuroscience are explored in this report.

PREAMBLE

The past 70 years have brought tremendous changes to human health. Many diseases which had devastating consequences before can now be successfully treated. Many others are now considered as chronic diseases, so that even those who are affected are able to lead a good life. Vaccinations, improved diagnostics, new surgical techniques, effective medical devices and safe medicinal products have been developed and thus alleviated the burden of disease. All these achievements have reduced child mortality and extended life expectancy and quality. Innovative techniques seem to provide new insights into human nature. Basic sciences, especially molecular biology and genetics, allowed us to find out secrets of our history. These substantial improvements would not have been possible without high quality science and research. To protect participants in these researches, many international documents were produced (Nuremberg Code, Declaration of Helsinki, CIOMS guidelines etc.), and the ethics that govern medical research has been continually elaborated and more widely accepted.

At the same time, it is observed that social distances in the world are disproportionate to the progress of science, and profound modifications of nature triggered new ecological worries. These challenges resulted in a new democratic, enlarged and progressive conceptual vision of “bioethics”. The “bio” is no longer a purely "biomedical" or "biotechnological" meaning. It incorporates into the agenda bioethical issues related to health (support for health services; access to quality health care and essential medicines – Articles 14 and 15 of the Universal Declaration on Bioethics and Human Rights), society (addressing marginalization and exclusion; reduction of poverty and illiteracy – Article 14 of the Declaration) and the environment (protection of the environment, the biosphere and biodiversity; adequate access to potable water – Articles 14 and 17 of the Declaration). Strict observance of ethical values is important as many challenges remain and there are many situations which might lead to discrimination or stigmatization of human beings. The International Bioethics Committee addresses some of these in the present report.

1 INTRODUCTION

In October 2005 the Universal Declaration on Bioethics and Human Rights (UDBHR) was adopted by acclamation by the General Conference of UNESCO. Article 25.1 of the UBDHR provides that:

> “UNESCO shall promote and disseminate the principles set out in this Declaration. In doing so, UNESCO should seek the help and assistance of the Intergovernmental Bioethics Committee (IGBC) and the International Bioethics Committee (IBC).”

In accordance with the Declaration, the IBC has written three reports that set out to clarify the meaning of several articles of the Declaration. The IBC Report on Consent was published in 2008, followed by the IBC Report on Social Responsibility and Health in 2010, and the IBC Report on the Principle of Respect for Human Vulnerability and Personal Integrity in 2013. At the same time, the IBC turned its attention to Article 11 of the UDBHR, which pertains to Non-Discrimination and Non-Stigmatization. This article provides that:

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

Throughout the development of the UDBHR the importance of an article on non-discrimination and non-stigmatization was always accepted, even though different formulations of the article were suggested. The result is an article that is really reduced to its fundamental content and therefore rightly can be called deceptively simple. The IBC, however, believes that there is room for clarification of the scope, meaning and application of this provision of the article, which will

be referred to here as the principle of non-discrimination and non-stigmatization, or simply “the principle”. This report starts with an explanation of the context in which this principle should be read, explains the meaning of the central terms – discrimination and stigmatization – and finally applies the principles to six contextual examples originating in domains related to medicine, life sciences and associated technologies as applied to human beings. They serve to illustrate some of the diverse situations where discrimination and stigmatization may occur in everyday life in modern societies.

2 EXAMINING ARTICLE 11

2.1 Discrimination

Every article within the UDBHR must be read in the context of the entire Declaration, as is stated in the Declaration itself. Article 26 states that:

> “This Declaration is to be understood as a whole and the principles are to be understood as complementary and interrelated. Each principle is to be considered in the context of the other principles, as appropriate and relevant in the circumstances.”

A review of other relevant sections of the Declaration indicates that Article 11 is firmly rooted in international human rights law. A major source for information on the context of the article is the preamble which mentions all the relevant foundational instruments of international human rights law. The most prominent of these references is the Universal Declaration of Human Rights of 1948 which in its first article states that:

> “All human beings are born free and equal in dignity and rights.”

Article 7 of the Universal Declaration of Human Rights is specifically concerned with discrimination and states that:

> “All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.”

Other important human rights documents are listed in the preamble of the UDBHR as well, such as the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women.

In conclusion, the scope of Article 11 is determined by the scope of the Declaration itself. Thus Article 11 applies to ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, political, legal and environmental dimensions. It is primarily directed at States, but provides also guidance to other parties. In this perspective, while providing several examples, IBC has formulated recommendations for courses of reflection and action to prevent or mitigate discrimination and stigmatization.

Turning to the scope of the principle itself, one can deduce from the wording that only those distinctions that impair human dignity, human rights or fundamental freedoms are rightfully called discriminatory under Article 11. A decision or a practice that is discriminatory is one that infringes upon these fundamental notions and such decisions or practices are objectionable. In this sense ‘unfair discrimination’ is a pleonasm and ‘fair discrimination’ and ‘positive discrimination’ are contradictions in terms. This is not to deny the importance of those legal provisions and ethical perspectives which make use exactly of the notion of ‘positive

discrimination', in order to even the conditions of disadvantaged groups and therefore respect, protect and fulfil the equal dignity of every human being. This is just to clarify the content and scope of the principle of non-discrimination within the context of Article 11.

The lottery of social and biological life should not be grounds for disadvantages or advantages. Examples of characteristics that should not be grounds for special disqualifications, harms and restrictions are sex, race, religion, political belief, national origin or sexual orientation. In the case of the several issues related to health care and building on the awareness that material conditions of human life are pervasive factors in its improvement, Article 14 of the UDBHR includes economic conditions as a potential basis for discrimination not to be tolerated. A specific attention to disability is required by the Convention on the Rights of Persons with Disability of 2006. Among other matters, Article 25 of the Convention prohibits "discrimination against persons with disabilities in the provision of health insurance" and calls for prevention of "discriminatory denial of health care or health services or food and fluids on the basis of disability".

Article 11 provides no list of grounds for discrimination or stigmatization. Indeed it explicitly states that discrimination or stigmatization on any ground is forbidden. Some may view this as a missed opportunity of emphasizing the risk of discrimination and stigmatization on certain grounds, but one could also hold that the principle as it stands is reduced to its fundamentals and as such, in its simplified form, has become even more robust.

Earlier versions of the Declaration contained a phrase that intending to discriminate as well as having the effect of discriminating fell under the scope of the article. This phrase was in line with the text of the Convention on the Elimination of All Forms of Discrimination against Women and the International Convention on the Elimination of All Forms of Racial Discrimination. In the process of the drafting of the Declaration that phrase was dropped. Given what was said above about the context in which the principle should be understood, one can safely conclude that the absence of this specific language in the final text of the principle by no means implies a divergence from the substance of those conventions. Article 11 therefore can be understood to speak to both direct and indirect discrimination and stigmatization.

2.2 Stigmatization

In contrast to discrimination, stigmatization is more of a social concern than a legal concept. In its more common meaning, a stigma is a mark of shame, disgrace or discredit. Many examples have long histories. It is common, for instance, for people to use labels for foreigners or people of other races, colour, social class or religion which are belittling. Usually the labels stereotype individuals of a given group and are always derogatory and insulting. They suggest that their bearers are feckless, or untrustworthy, or dangerous, or unclean, or evil, and so on.

To impose a stigma upon a person is to render that person easier to treat with disrespect. Thus if someone is an 'infidel', a 'heathen' or a 'primitive', for example, then one might find it easier or even obligatory to treat them in ways which would be abhorrent with respect to members of one's own social or national group. History is replete with examples of such behaviour even in modern times where propagandist descriptions of specific groups of people such as vermin and parasites have been used to desensitize populations and enable them to permit or execute dreadful acts upon fellow human beings.

The stimuli for the use of labels of this sort are various but fear and ignorance are the most prominent. All people will have grown up surrounded by prejudices of various kinds associated with national identity, physical appearance, religious differences and so on. In times of economic depression or shortage of resources where one's own interests are threatened, or in times of turmoil when in search for a scapegoat to explain the suffering it is not uncommon for

these prejudices to colour one's judgment and influence one's actions. It is interesting that one of the most familiar labels applied to people who are ostracized from society and rendered less worthy of social benefits is the term 'leper'. This medical term reminds us that medical conditions can themselves stigmatize persons.

Whereas non-discrimination can be said to be firmly rooted in international human rights law, the same cannot be said of the concept of stigmatization. Perhaps one could even say that stigmatization is included in the concept of discrimination, in the sense that certain characteristics that engender discrimination may also be stigmatizing and stigmatized human beings, inasmuch as they are considered of less worth and inferior to their fellow citizens, are subject to discrimination. Fighting against discrimination and stigmatization represents the recognition of equality between human beings, their dignity and the principle of justice in their relations.

One of the first international documents that speak of stigmatization is the International Declaration on Human Genetic Data, adopted by UNESCO in 2003. Article 7a of this document holds that:

> "Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing, human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities."

This article must be read against a background of the threat or danger of stigmatization of individuals or groups as a result of population based genetic studies which might suggest that certain groups are inherently inferior. Article 11 of the UDBHR highlights the necessity to broaden this perspective, looking at the presence of these behaviours in the wide scope of medicine, the life sciences and associated technologies.

It is clear that one of the most likely scenarios in which to encounter them is in the availability and distribution of healthcare where the need will always outstrip the resources available. Here the Article is seen to be intimately related to Articles 8, 10, 13, 14 and 15. The historical emergence of the medical term 'leper' as a stigmatizing label has already been mentioned. There are more modern examples emerging. There are medical diagnoses which can impose major social limitations on patients. AIDS is a prominent example where social ostracism has followed diagnosis in many cases and imposed enormous burdens on sufferers. This case is similar to leprosy in some respects but entails an additional risk of stigmatization, related to the alleged personal 'responsibility' for the behaviors that facilitate the transmission of the condition.

Other diagnoses may imply blame on the part of the sufferer. Obesity provides an example. In this case the solution is often thought to lie in the hands of the patient viz. to modify eating habits. Such generalized attributions have been properly called 'victim blaming' and tend to oversimplify patient conditions and disrespect the sufferer. Other examples which have no element of blame attached to them, such as diagnoses of mental illness, have also traditionally stigmatized sufferers together with diagnoses of disabilities. The shorthand description of such patients as 'handicapped or disabled persons' rather than 'persons with handicaps or disabilities' suggests that they are lesser persons in some sense which undermines their dignity.

3 APPLICATION: CONTEXTUAL EXAMPLES

There is of course no definitive list of discriminatory or stigmatizing practices. These practices will change over time. Some practices are clearly discriminatory and need no comment. The only thing needed in those cases is action: naming, shaming, prevention, and punishing, i.e.

legal intervention. In other cases, however, the risks of discrimination or stigmatization are not so clearly discernible. Sometimes practices that at first sight do not seem to entail risks of discriminatory or stigmatizing effects, on closer examination do turn out to entail such risks.

The IBC has therefore decided to examine a number of contextual examples in order to identify possible risks for discrimination or stigmatization, foster awareness and give specific recommendations for policy-makers. To this end, the Committee strongly encourages relevant authoritative bodies to take into account several considerations when analyzing policies or practices with regard to their discriminatory and stigmatizing causes and effects. First, it should be clear against whom discrimination and stigmatization may occur, including certain individuals, particular social groups and whole populations. Second, discrimination and stigmatization must be identified according to which criterion it does or could occur, in terms of personal and/or social traits. Third, the sources of discrimination and stigmatization must be addressed. Fourth, the manner of discrimination and stigmatization is to be identified. There may be for example harmful attitudes, social practices or legal consequences. Fifth, the concrete consequences of discrimination and stigmatization must be scrutinized, such as access to health care, exploitation or social disqualification. Sixth, the appropriate manner to address the problem should be explored, i.e. public awareness, policy change, etc.

Generally speaking, poverty, racism and sexism are examples of persistent problems for societies. In the context of modern medicine and science, persistent problems that involve discrimination and stigmatization, assessed in this Report, are access to medications for neglected diseases, HIV/AIDS with the burden of stigmatization that it still carries, and organ donation, transplantation and trafficking. As persistent problems they are unfortunately familiar, although they have evolved in certain details. There are also emerging scientific and technological developments that could aggravate persistent problems or even create new versions of these problems, however admirable and valuable these scientific and technological developments might otherwise be. The subsequent chapters will explore biobanks, nanotechnology and neuroscience.

The examples are of course not context-free. They were chosen in 2011 because they were identified as major developments within medicine and science at that time and are actual or potential sources of discrimination or stigmatization. It is by no means claimed that the cases discussed in this report are the only ones in which discrimination or stigmatization might occur, nor that these are the most risky ones in this respect. It is also easy to anticipate that the emerging issues mentioned will have a growing impact on everyday life: expert bodies – starting with the IBC itself – and public opinion will keep focusing on them and their broader ethical implications. However, the Committee believes that they serve also as useful examples for an exploration of problems of discrimination and stigmatization in the context of modern medicine and science.

At the same time, the Committee recommends that governments, other institutions, all sectors of society, and individuals apply the method of analysis illustrated herein not only to these but also to other persistent and emerging problems, building on the awareness that the responsibility of applying principles may call for differentiated action, in order exactly to realize them. A telling example is the case of women and girls, who require differentiated medical care for sexual health and maternity. The “difference” of being a woman in this world often entails a major risk of not sharing equal rights.

4 PERSISTENT PROBLEMS

4.1 Neglected Tropical Diseases

4.1.1 Latest Developments in the Field

Neglected Tropical Diseases (NTDs), also referred to as Infectious Diseases of Poverty are diseases that affect mostly the poorest of the poor populations living in remote, rural areas – often conflict zones in developing countries. More than one billion people worldwide are affected by NTDs (WHO, 2009). NTDs are serious disabling or life threatening diseases for which diagnosis is difficult and the treatment options are inadequate, toxic or nonexistent. NTDs have received little attention in terms of research and resources despite their magnitude and impact on economic development and quality of life. In 2012 the World Health Organization (WHO) and partners including pharmaceutical companies, donors, NTDs endemic countries and non-governmental organizations came together under the umbrella of the London Declaration to control or eliminate at least 10 NTDs cited in the WHO 2020 Roadmap on NTDs. According to the WHO Special Programme for Research and Training in Tropical Diseases (TDR), there are a total of 17 NTDs (WHO NTD Global Report 2012) and WHO has recommended a revision of these NTDs to include three more diseases. NTDs continue to cause significant morbidity and mortality in developing countries as the vicious cycle between infection, poverty and weak health systems persists.

The current system for research and development (R&D) for evaluating new compounds to treat NTDs has been underfunded for many years and does not adequately meet the needs of the poor communities. This anomaly in health research investment in developing countries is attributed to poverty, lack of research capacity, weak institutions, lack of communication and infrastructure in general, inability to translate research findings to policy, and weak drug regulatory systems within the Ministries of Health. Between 1975 and 2004 only 21 (1.3%) of the 1,556 new drugs approved were specifically developed for tropical diseases even though these diseases account for 11.4% of the global disease burden.

Owing to a combination of market and public policy failures, drug development has largely been confined to the R&D based pharmaceutical industry which focuses mainly on global diseases and lifestyle conditions. Therefore, these diseases remain neglected in that they do not constitute a lucrative market and the neglected patients have no purchasing power as they live in poverty in marginalized remote underdeveloped areas. The weak research capacities in developing countries are compounded by poverty and this is less attractive to potential collaborations or sponsors for drug development. The lack of basic science research funding and manufacturing capacity in developing countries hinders innovation and capacity building. This picture is now changing slowly with interest shown by some Private Public Partnerships (PPPs) or Product Development Partnerships (PDPs).

The WHO Consultative Expert Working Group on Research and Development: Financing and Coordination (CEWG) was established by the World Health Assembly (WHA) in 2010 with the aim of taking forward the work that was previously done by an Expert Working Group on R&D: Financing and Coordination on diseases that disproportionately affect poor countries. A report was provided to the WHO by CEWG and was discussed in May 2012 by the WHA. The WHA adopted a resolution, EB132.R7 on NTDs in May 2013 which calls upon WHO affiliated member states to carry out more activities on NTDs to facilitate integration of prevention, control, treatment, elimination and eradication of these diseases. Further discussions are still ongoing on the way forward in improving R&D, financing, coordination and monitoring of research.

The available drugs for neglected diseases have an inconsistent supply. Some of them rely on a single supplier. This means that the supply of these drugs may be interrupted and treatment needs of the suffering patients will go unmet.

4.1.2 Discrimination and Stigmatization Risks

More than one third of the world's population has no access to essential drugs and more than a half of these people live in the poorest regions of Africa and Asia. The lack of access to medicines for economic reasons contravenes the provisions of Article 2 of the Universal Declaration of Human Rights and Article 14 of the UDBHR, which points out the differences of economic conditions as an unacceptable basis for substantial differences as to the access to quality health care and therefore as a possible source of "discrimination" in the broader sense of the term.

In addition, patients with NTDs are a stigmatized and discriminated group that is disadvantaged because of the situation in which these people find themselves. The clinical presentation of some of these NTDs is so disfiguring that some of the patients suffering from these NTDs feel stigmatized and discriminated and this may prevent them from seeking help and treatment. This discrimination, which derives from self-perception and others' perception of the affected individual, should be addressed through education on the particular disease but also on the acceptation of differences, on compassion for and solidarity with people who are suffering, in line with the values enshrined in the Declaration.

Patients suffering from Chagas Disease, Leishmaniasis, Human African Trypanosomiasis also known as African sleeping sickness and elephantiasis to name but a few, often experience stigmatization. This can lead to fear and belief that the disease is self-inflicted or due to other forces such as evil spirits or witchcraft.

Women and children suffer the most when they contract NTDs. During pregnancy the immune system is low leaving the mother to be more prone to diseases including NTDs. NTDs disfigure and stigmatize mothers and children who may as a result be hidden from the public thus denying them management of their condition. Women's and children's health needs to be protected.

4.1.3 Courses of Reflection and Action

Patients suffering from NTDs may be too sick and weak to travel long distances to seek treatment for their condition, let alone pay for their treatment. A significant underlying problem of weak health care systems in many developing countries where NTDs are endemic remains that of access to medication. Procurement and distribution systems for medicines in many developing countries are weak and sometimes dysfunctional. Some countries have a central system which then distributes medicines to the rural communities. These central units are not working optimally thus making access to drugs sub optimal. These same countries are also struggling with issues of production and supply of medicines and the proliferation of counterfeit medicines in the market. It is not ethical to treat patients with sub-standard counterfeit medicines.

The available drugs that treat NTDs are expensive thus making access by the poor communities limited. In the areas where some NTDs occur, there is political, economic as well as environmental instability. In too many cases governments are falling short of meeting their responsibility to look after their citizens. Hard choices must be made about improving the political and economic environment and health care spending in relation to other government expenditures, including the military. The assumption by patients and by their families of their right to health care, and the solidarity of the health teams and the organized society can encourage governments to respect the right to health of these persons and to implement appropriate programmes.

NTDs are primarily diseases of developing countries and drugs to treat these diseases need to be evaluated at the point of registration in developing countries. However some of the regulatory authorities in these neglected disease endemic countries lack capacity to evaluate registration

dossiers as well as Good Manufacturing Practices (GMP) of companies. Collaboration between Ministries of Health and the WHO pre-qualification programme for evaluating drugs could speed up the pre- qualification process for NTDs and enable Ministries of Health to include these drugs in their essential medicines list thus improving treatment options and availability of medicines for patients who need them most. Health-related international organizations have the responsibility vis-à-vis these patients and must contribute to develop programmes to help these populations

Human African Trypanosomiasis or sleeping sickness is endemic in 36 countries of sub-Saharan Africa and over 60 million people are at risk of contracting this disease, which is fatal if left untreated. Currently about 30,000 people are known to be infected, but 48,000 persons died of it in just 2008. Most of the available treatments have serious side-effects, and one of the most effective drugs for treating this disease has an interesting history. It was initially introduced as an anti-cancer drug, but later trials proved it was effective against sleeping sickness and it was approved by the US Food and Drug Administration in 1990 and used successfully in Africa. However, in 1995 it met a fate not uncommon for drugs destined to treat neglected tropical diseases – its production was discontinued by the only company which made it. Even though this company licensed the drug to the World Health Organization the stocks ran out in the year 2000 and nobody was willing to produce it, until eflornithine found a different, unexpected and much more lucrative use: applied to the skin it prevented unwanted facial hair growth in women, and in consequence, as described by the New York Times “a Beauty Regime Salvaged a Cure for Sleeping Sickness”. Production was resumed and currently the drug is effectively used to treat sleeping sickness.

The use of Trade Related Aspects of Intellectual Property Rights(TRIPS) flexibilities by governments, the policies of patent holders and availability of increased funding to support treatment programmes provide new fruitful opportunities. In compulsory licensing, in particular, the government allows someone else to produce the patented product or process without the consent of the patent owner. In the patent system, the compulsory licenses have two aims: one is to allow society to share the benefits of scientific progress in specific circumstances such as national health emergencies and the second is to boost the industrialization of the country in question. Although compulsory licensing should not become the rule (that would destroy the delicate balance between R&D, intellectual property and health needs) it could be considered in some cases of NTDs.

More than one billion people worldwide are affected by NTDs. Over one third of the world’s population has no access to essential medicines and more than half of these live in the poorest regions of Africa and Asia. Poverty, lack of R&D, poor infrastructure, weak health systems and drug regulatory systems all add to poor access to drugs. Poor people with NTDs are stigmatized, discriminated and have no voice, so there is need to empower them to form groups to lobby their governments to do more. Governments need to take responsibility for their citizens and engage more in innovation and have political will to identify ways to strengthen health infrastructure, improve delivery of services including access to drugs for the poorest populations with NTDs, and create stable political and economic environment. Procurement and distribution systems for medicines in many developing countries are weak and sometimes dysfunctional. There is also need to improve translation of product development research results into policy leading to uptake by poor communities. A stronger partnership between countries, policy makers, researchers and communities is also needed.

4.2 HIV/AIDS

4.2.1 Latest Developments in the Field

More than thirty years after the first case of AIDS identified in the United States, followed by the isolation of the HIV and development of the first diagnosis and treatment technologies, stigmatization and discrimination of persons with AIDS persist. The problems are complicated by barriers to access to health services, to diagnosis and to antiretroviral drugs (ARVs). Certain interventions, such as circumcision as a prevention measure and behavioral methods that focus on more vulnerable sub-groups, exacerbate even more the debate on stigmatization and discrimination and bring to the forefront matters of human rights and bioethics as strategic references for public health.

Budget constraints in managing the ongoing HIV/AIDS epidemic operate at all levels, from competition for other uses of public funds to allocation for various diseases, especially in developing countries. Even within the budget for AIDS, decisions must be made in relation to the allocation of funds for different situations: caring for the already ill, screening of donated blood, education, prevention and research on treatment. Thus, the most efficient application of existing resources, the setting of limits on the actual available resources, the pressure for more resources both internationally and domestically are only a few of the challenges to overcome.

There is no doubt that the AIDS epidemic has inflicted irreparable losses and suffering on populations, but it is also undeniable that it has brought advances in terms of reflection and changes in health systems throughout the world. The response to the epidemic has had significant impact on the improvement of health care systems, on scientific and technological development, on building intersectorial and multidisciplinary responses, and community participation. Above all, it was responsible for defining the human rights and bioethics debate on the international agenda as prerequisites for overcoming the majority of present day public health problems. At the same time, the AIDS epidemic has shown that discrimination and stigmatization are barriers to its effective control as they make it more difficult for the affected individuals to access the needed health services.

There are established ethical and social principles in each of the aforementioned issues, but they are not internationally recognized and in many circumstances are not even agreed within a given country. In liberal societies, ethical and pragmatic policies have contributed to the adoption of public health strategies that stress mass education, counseling and respect for privacy. Even nations with similar backgrounds and levels of development have differed in their approaches to the problems brought up by the pandemic, such as who should be tested; the demand for testing to get entry visas; contact notification; reporting of HIV infection; and coercion of people living with or affected by HIV/AIDS.

Urban poverty is strongly associated with the HIV/AIDS burden. According to the World Bank, the urban misery will be the most explosive economic and political problem in the 21st century. The emergence of megalopolis, cities with more than 10 million inhabitants, will stress the health systems even more. Today 20 out of the 25 largest urban centers are concentrated in the poorest parts of the planet.

Much has been written about the enormous economic burden of the AIDS epidemic, including the direct (medication, out-patient care, hospices, hospitalization) and indirect costs (research, education, prevention, loss of GNP). Even with all the possibilities of lowering the expenses by a more coherent societal approach (family, friends, non-governmental organizations, day-care clinics), the need to effectively control the epidemic are much greater than the resources put in place to pay for them. It must be emphasized that in most of the developing world, HIV infection is added to a list of diseases already endemic (e.g. schistosomiasis, Chagas disease, leishmaniasis, chronic hepatitis, malaria, and leprosy).

In 2012 it was estimated that more than 34 million people were living with HIV. The scaling up of access to ARVs in the last decade, accounting for an increase of 27% in low and middle income

countries, has represented a decrease in AIDS-related deaths and improved the quality of life of people living with HIV. Despite the progress made, there were approximately 2.7 million new infections in 2011. In addition to that, access to treatment continues to be a challenge for many poor and developing countries. The asymmetry of access to essential medication on a global scale reflects the inequalities imposed by the current global economic system. Despite the flexibilities of the TRIPS Agreement, such as parallel importing and compulsory licensing, and the 2001 Doha Declaration on the TRIPS Agreement and Public Health affirming the States' right to make use of these tools, the absence of local industrial capacity and the lack of alternative external markets reveal its limitations and the imbalance of power among countries.

For many decades, international collaborative research on HIV/AIDS has usually been developed, funded and wholly designed in developed countries, involving researchers and institutions of these countries. It has been run through the funding, research staff, institutions and in many instances the whole project design of a developed country, and then undertaken in institutions within developing countries.

In recent years, the WHO has championed the search for answers to global health and, in particular, in relation to HIV/AIDS, with the establishment of UNAIDS. It has also played a substantial role through Tropical Disease Research (TDR), funding research on different diseases. The establishment of the Global Fund for HIV, Malaria and Tuberculosis and UNITAID amplified both the establishment of needed research and the access to medicines, with effective participation of all countries.

Research ethics standards that are widely recognized and accepted include the need for informed consent, the careful balancing of risks and benefits, and confidentiality. The practical difficulties of applying these standards are by no means unique to HIV-related research, but the particular characteristics of the epidemic have magnified some points. In relation to International Collaborative HIV Research, these include the need for culturally relevant consent, risk assessment and confidentiality provisions; collaboration of research workers from developed and developing countries at every stage of the study; equal sharing of benefits and burdens of the research; research capacity building; and consultation with vulnerable groups. It should be also considered that people who participate in a research may have their illness publicly recognized. In these cases, confidentiality must always be ensured.

4.2.2 Discrimination and Stigmatization Risks

Stigmatization is produced socially, reinforces inequalities and contributes to the worsening of the inequities and vulnerabilities of certain individuals or groups. It compromises individual and collective health conditions by hindering access to health services and to prevention and treatment actions, as affected individuals who fear that they will be discriminated against do not seek needed health care.

Article 13 of the Declaration of Commitment on HIV/AIDS signed by the Member Countries at the United Nations General Assembly Special Session on AIDS (UNGASS) underscores that stigma, silence, discrimination and lack of confidentiality increase the impact of the epidemic. Moreover, the UN also concurs that stigmatization creates obstacles to overcoming AIDS, as the marginalization of more vulnerable populations hinders access to universal prevention and treatment; that treatment and prevention are capable of putting an end to new infections but it may not reach those most at need. Those living with HIV who are stigmatized by the disease include intravenous drug users, gay men, sex workers, transvestites and transgendered persons, given that, in many countries, they are criminalized or punished. The 2012 UNAIDS Report also made clear that countries with discriminatory laws and regulations should

immediately remove them, as a demonstration of their commitment to the effective control of the epidemic.

Pedrito was a very intelligent boy. At 3 years of age he was at the top of his class in pre-kindergarten. His father, who was HIV-positive, left the family, and his mother decided to move from the rural area where they lived to the closest city. Excited by Pedrito's precociousness his mother made efforts to send him to a special school for the gifted and talented, and to afford the tuition she went to work at a fabric factory. Pedrito easily adapted to the requirements of the new school. A month later, his mother received a letter from the school principal stating that Pedrito had been removed from the school due to his father's HIV status. The mother met with the principal to reassure him that neither she nor her son was infected with HIV. She was told that both of them were required to have a HIV test done. She refused to be tested and decided to return with Pedrito to the rural area where they had previously lived.

The AIDS epidemic has exposed tensions in many areas of public policy with regard to discriminatory and stigmatizing practices. These include the criminalization of HIV transmission; travel restrictions imposed on people living with HIV; discrimination in the workplace and at school; the population's lack of knowledge about the disease; the social rejection of certain groups; and the new health needs of people living with HIV, mainly arising from treatment side effects, as in the case of lipodystrophy, which has been referred to as the "new face of AIDS" and has been associated with the exacerbation of stigmatization and discrimination. There is as well a "new generation" of people living with HIV caused by mother-to-child transmission, who are discriminated against and stigmatized as a "heritage" from their parents.

Especially in contexts of concentrated epidemics, when the most vulnerable groups are precisely those most stigmatized, it is necessary to identify ways of directing actions to these groups as a priority, although in such a way as not to exacerbate the stigmatization they already bear.

Health systems and health personnel may contribute to discrimination and stigmatization of people living with HIV/AIDS by treating their condition in a manner different to that of other communicable diseases. This may convey the idea that it is a more secretive and shameful disease and thus reinforce negatives stereotypes.

4.2.3 Courses of Reflection and Action

The experience of countries with an effective response to the AIDS epidemic confirms that it must be based on democratic values and social participation. The recognition of vulnerable groups as active subjects, as stakeholders in the very process of building this response, together with the respect for human rights and the recognition of the right to health care has proved to be paramount. The participation of the most vulnerable groups is essential for the actions to be successful for a variety of reasons. They can present their health needs, pressuring for the scaling-up of access to health services, for the quality of these services and for the timely and universal access to diagnosis, prevention and treatment commodities. Through their efforts for the right to health care, they can take recourse to different power centers, such as the legislative and the judicial branches, in order to guarantee this right. By bringing with them their knowledge and experience, they can contribute to the construction of responses that are more appropriate to the specific circumstances of each group.

Article 26 of the UDBHR recommends respect for "Interrelation and complementarity of the principles". In this sense, the importance of the relationship between the principles of "Non-discrimination and non-stigmatization" and "Solidarity and cooperation" needs underlining. Solidarity actions, developed with rigour and fairness and based on the

direction set by the political necessity of international cooperation between countries and peoples, are able to improve the quality of life for many peoples, nations and countries. The implantation of industries of diagnostics, vaccines and drugs in developing countries, sponsored by industrialized nations without the sole purpose of economic gains, but related to a sincere support with knowledge transfer and technology, can turn into a vector of concrete technological independence and empowerment in recipient nations, directly contributing to the reduction of stigma and discrimination in relation to the issue of HIV/AIDS.

4.3 Organ Donation, Transplantation and Trafficking

4.3.1 Latest Developments in the Field

In an ideal world, voluntary, anonymous and free organ donation illustrates a society's principles of solidarity and altruism to perfection. As the values conveyed by organ donation are prime importance, they should not be marred by any hint of discrimination and/or stigmatization. In reality, however, the dearth of organs and the opening up of borders pose new ethical challenges as these principles are being violated.

According to a report by the Global Observatory on Donation and Transplantation (GODT), 106,879 solid organs were transplanted in 91 countries worldwide in 2010. However, resources, laws and sources of organs vary considerably from one country to another. Whatever the strategy adopted, the gap between organ supply and demand is widening steadily in all countries. Indeed, it is estimated that only 10% of world requirements are currently being met (GODT, 2010). Between 15% and 30% of people on organ waiting lists die before they receive an organ.

Organ transplantation is one of the major breakthroughs of twentieth-century medicine and offers an unprecedented opportunity to save tens of thousands of patients, improving their quality of life and that of their families. However, the transplant system is wholly dependent on organ donation. Although organ donation is a social issue, it has to date been confined to the private domain of medicine, but is in fact a matter of concern to all.

National and international efforts have hitherto failed to stop the development of the organ trade, transplant tourism and even organized organ trafficking in some parts of the world. Such activities are not inevitable, and organs are transplanted in many countries under exemplary ethical conditions, despite the short supply.

Contrary to the ethical principles explicitly stated in the international and national declarations adopted to regulate organ transplants, the principles of non-stigmatization and non-discrimination have never been clearly highlighted. Indeed, stigmatization and discrimination were not explicitly addressed in the 2010 WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation, the 2008 recommendations of the Asian Task Force on Organ Trafficking, the 2008 Declaration of Istanbul on Organ Trafficking and Transplant Tourism as well as the 2010 Madrid Resolution on Organ Donation and Transplantation. Furthermore, while the Council of Europe's initiative aimed at combating organ trafficking (2012) included a criminal law convention against these practices, it did not address the risks of stigmatization and discrimination. Lastly, in its efforts to prevent human trafficking (2000), the United Nations acknowledged the link between organ trafficking and human trafficking.

4.3.2 Discrimination and Stigmatization Risks

Organ donation

Although the ethical issues differ for cadaveric and living donors (whether related or not), there is a grave risk that the most vulnerable social categories might be exploited because of their reduced ability to defend themselves and make their own choices autonomously. Such exploitation must be combated.

In order to avoid the discrimination, stigmatization and exclusion of some groups of people, national health systems and public bodies in charge of transplants bear the responsibility of striking a balance between donors and recipients on the basis of purely medical criteria. As it is a question of donations and of human organs, exceptionally stringent ethical vigilance must be exercised over management of the organ shortage.

Efforts to encourage citizens to donate organs often appeal to a noble sentiment. However legitimate those efforts, they must not overlook the importance of a society's values. It should be remembered that the number of donations and the quality of the organs donated depend on the organization in place for such purposes in a country. That said, the scientific and ethical standards acknowledged in those regards must remain inseparable from societal values and religious or other beliefs. The one is not possible without the other.

Consent

In theory, donation is always a laudable action, provided that all conditions of free and informed consent are guaranteed.

In practice, however, legislation that introduces presumed consent can discriminate against the least educated, immigrants, people living alone or the most marginal members of society. In some circumstances, those people risk becoming an almost exclusive category of organ donors, simply because they cannot expressly refuse, if they wished to do so. The same applies when people are required to register their wish not to have their organs removed.

In order to offset the shortage of human organs, several countries have adopted a policy of "presumed consent". This policy, designed to increase the number of organs available for transplants from deceased donors, rests on the presumption that people in the society in question are usually willing to donate their organs after their death; their organs may consequently be removed after death without their prior consent. Under the policy of presumed consent, people who are opposed to deceased organ donation may decline in writing. This policy can discriminate against people who do not express their wish owing to social exclusion, or who might become donors but are unlikely to be familiar with the legislation on presumed consent or avail themselves of the means of expressing opposition.

Living donors

As donations from unrelated donors are always underlain by ethical concerns, absolute rigour is required in the approach taken.

In the case of an identified recipient, even when consent to the donation seems to have been given freely, there is a risk that organs for socially privileged patients will be obtained only from underprivileged and vulnerable people.

In the case of related donors, the most vulnerable members of the family are also most likely to be donors, in particular women, whether they are the wife or an unmarried girl. Even where clearly established regulations are in place, there have been reports of many marriages of convenience, entered into to make the wife a donor.

Organ transplantation

Access to quality health care, when influenced by socio-economic conditions, is a source of discrimination.

Some organizations include living conditions as a criterion for a patient to be given priority on their transplant waiting lists, thus discriminating against the most vulnerable members of society. The same applies to age limits, people living alone or patients with other diseases. In short, transplant exclusion criteria sometimes reflect a desire for the medical teams to be successful rather than concern for the patients. In establishing medical criteria it is important to ensure that those criteria do not cause stigmatization or discrimination.

Organ "tourism", trafficking and trade

Due to the lack of donors or suitable transplant capacities in their country, many people consider it acceptable to travel abroad to receive a transplant. In so doing, they can transgress the ethical foundations that underpin this activity in its entirety.

Vulnerable members of society, such as the illiterate and poor, undocumented immigrants, prisoners and political or economic refugees from poor countries constitute the organ pool in certain parts of the world.

Organizations and intermediaries exploit donors' and recipients' desperation. There is a flourishing illegal market for organs, and organized organ trafficking is spreading throughout the world. Indeed, it is estimated that such trafficking accounts for 5% to 10% of all kidney transplants performed worldwide each year. Governments and international organizations first acknowledged organ trafficking and exploitation of vulnerable people as worldwide problems more than 20 years ago.

Organ trafficking is an unacceptable commodification of human beings that thrives on the donors' and recipients' distress. The weakest are the first to be hurt by the law of supply and demand. It is a negation of human dignity. People whose organs are removed in a trafficking environment are actually victims, even if they have given their consent.

For those victims of organ trafficking and tourism, there is also a high risk of stigmatization in their societies. They are caught in a vicious cycle of exploitation, discrimination and stigmatization. In some cases they are not reintegrated into their community after falling victim to organ traffickers. Many studies show that people who sell their organs are usually desperate and in need of money to survive or pay debts. To the detriment of their health, some are reluctant or unable to receive follow-up medical care after the organ has been removed.

The medical care required after a transplant is not available in the organ trafficking or trade context. Recipients often suffer serious complications owing to infection risks as well as mediocre donor-recipient compatibility and initial immunosuppression protocols. Recipients of organs obtained through trafficking and/or transplant tourism not only run medical risks, but also face stigmatization, for, when they return to their country of origin, these recipients are often (rightly) considered to have contravened the system.

In order to be effective, the action to combat the commodification of human organs should consider all actors involved, including organ recipients. There is no doubt that international governance is of utmost importance in this regard.

4.3.3 Courses of Reflection and Action

Owing to the chronic dearth of organs, the lack of data and the inadequacy of national and international regulations, the principles of equality, individual rights and human dignity have been violated. The risks of discrimination and stigmatization are not only associated with

unethical organ transplants, involving organ sales and trafficking, but also with lawful organ procurement systems.

To prevent discrimination and stigmatization linked to organ sales and trafficking, national and international health authorities must strengthen their cooperation and adopt the necessary policies to combat this phenomenon globally. In this perspective, initiatives such as the aforementioned Convention against Trafficking in Human Organs of the Council of Europe are a promising step forward.

Countries that have established public agencies to supervise organ donations and transplants have won their people's trust and have established impartial programmes. These public agencies should hold sole authority to license approved centres to remove and/or transplant organs in accordance with internationally recognized standards.

National efforts should be made to organize and encourage all forms of legitimate organ donations and thus ensure self-sufficiency. The introduction of an effective, transparent and reliable deceased organ donation system is the key. At the same time, it is important to develop specific instruments of cooperation for those small countries where this goal is more difficult to achieve. In this regard, the experience of Eurotransplant provides an illustrative example. Regional cooperation has been suggested also for those countries which lack transplant technology, so that they can address their transplantation needs (Declaration of Istanbul 2008).

As the exploitation of women is still a serious risk in many countries, more restrictive rules could help ensure close and stable relationship between donors and recipients (such as a minimum prenuptial period). Other policy solutions could be as or even more effective to enhance the protection of potentially vulnerable people. In order to avoid the exertion of family pressure on the most compatible members and ensure that all members of the family effectively have freedom of choice, for instance, information on the compatibility between potential donors and the recipient must be kept confidential. This would prevent stigma within the family if one chose not to donate her or his organ. The medical team in charge of the transplant is responsible for providing information on ways and means of withdrawing consent.

Organs from deceased donors currently offer the best compromise between science and ethics. Extremely rigorous ethical guarantees are required for unrelated living donors. The commitment to eliminating any sale or trafficking paraded in the guise of altruistic donation must be stated nationally and internationally. Financial assistance for organ transplants abroad must be forbidden, if the organs have been deemed objects of organ trafficking. Victims of these violations must be neither discriminated against nor stigmatized. It is the responsibility of health systems to protect organ donation and transplants as the common ideal, for it is the only therapeutic option open to many patients and the ideal solution for others in terms of life expectancy, quality of life and cost.

The establishment of an independent ethics committee to assess organ donors and recipients would be a salutary measure, as it would help to prevent stigmatization and discrimination on account of the organ transplant.

Ethical requirements demand that action be taken under organ transplant schemes to prevent discrimination and stigmatization. Poorer populations currently constitute a major source of organs for transplant through organ trafficking and/or transplant tourism; donors are thus caught in a vicious cycle of discrimination, stigmatization and exploitation. These risks are not confined to unethical organ transplant practices, such as the sale and trafficking of organs, but also arise in conventional organ procurement systems. As organ transplant is dependent on organ donations, efforts should be made to implement the existing international recommendations and guidelines, and to provide

public awareness and education. It will then be possible to work towards achieving organ self-sufficiency for a given population and avoid the exploitation, stigmatization and discrimination associated with organ transplantation.

5 EMERGING PROBLEMS

5.1 Biobanks

5.1.1 Latest Developments in the Field

The term biobank refers to collections of biological material (blood, tissue, DNA etc.) whether collected as part of routine health care or as research-oriented cohort studies[1]. Although the word biobank is relatively new, systematic collection of patient-derived samples is an old institution. Health care legislation of many countries considers routine collection and storage of human samples, originally obtained for diagnostic purposes, as an obligatory part of the quality control system of health care. When combined with different health-related registries, such biobanks can reveal important information on individual patients, and provide much-needed information on efficacy of different treatment modalities. Long-term storage of samples is important as this makes it possible to follow the progression, remission or relapse of a patient's disease, its response to treatment and allows reclassification of the disease when molecular diagnostic tools are developed. In addition to the disease orientated biobanks described above, large sample collections of population cohorts have been established in many countries. Such population biobanks comprise samples from healthy volunteers who have given a broad consent for longitudinal analysis of their samples and data.

Over the past 10 years, establishment of biobanks has become a global goal. In addition to OECD, several other organisations have recognized the importance of biobanking. In Europe, ESFRI (European Strategy for Research Infrastructures) included BBMRI (Biobanking and BioMolecular Resources Research Infrastructure) in its first Roadmap in 2006, and the resultant pan–European biobank (BBMRI-ERIC) was inaugurated in September 2013 and becomes operational in early 2014. Also the Innovative Medicines Initiative (IMI) is supporting several biobanking projects as public-private partnerships. The Public Population Project in Genomics and Society (P3G) is an important international initiative, which together with the International Society for Biological and Environmental Repositories (ISBER) and the WHO and its International Agency for Research on Cancer (IARC) emphasises the global importance of biobanking for the development of evidence-based health care. An important problem in biobanks is how the samples themselves, access to them and the data generated by the biobank activity are regulated. In principle genetic information will increasingly become part of the health information of every individual that should be stored in the medical records for future use. If the sample is used for research purposes, all identifiers are removed from the published data. However, the DNA sequence itself is a truly unique identifier of every human being. The progress in genetic techniques has led to the great facilitation of identifying individuals even on the basis of very little information. A sample can be detected and identified in a mixture of many hundreds of DNA samples. Any release of information or its access by unauthorized individuals may generate information which could lead to an undue burden on some biobank donors, and possibly to their stigmatization or discrimination. Moreover, it has recently been shown that

[1] The 2009 OECD Guidelines on Human Biobanks and Genetic Research Databases define biobanks and genetic research databases as "structured resources that can be used for the purpose of genetic research and which include (a) human biological materials and/or information generated from their analysis; and (b) extensive associated information."

some of the anonymous samples in publicly available databases can be identified through additional data linked to the samples, which makes access to biobank data and the content of public databases a matter of concern. With the increased sensitivity of sequencing technologies, the issue of identification of individuals through genetic analysis must undergo a thorough revision. Some countries already have legislation in place to prevent use of genetic information for discrimination of individuals. On the other hand, use of genetic information has been accepted for forensic purposes and investigation of serious crimes.

5.1.2 Discrimination and Stigmatization Risks

There are at least three interlinked developments that increase the danger of stigmatization and/or discrimination in relation to biobanking: (1) technological development itself, (2) participation rules in modern biobanking activities, and (3) the predictive nature of DNA.

Technological development of research methodologies in the field of molecular genetics has made it possible to use both new and old stored specimens to determine the complete genetic composition (DNA sequence) of an individual at a cost which has come down to a level making this procedure feasible both in clinical settings and for research purposes, even though this cost remains not affordable for many people in the world, highlighting the risks of a just market-oriented approach as well as the responsibility to curb its effects. Already today the internet lists several commercial services where one can have his/her DNA analysed.

Use of old patient samples from clinical settings or cohort studies is not without problems. Typically, medical care has been given without asking the patient for consent to use his/her samples for further studies on the disease, as this was considered to be a normal part of medical treatment. Only during the past 10-20 years, the requirement to obtain an informed consent from a sample donor, whether in a hospital setting or for a newly established biobank, has been in place. In some countries old sample collections have been transferred into biobanks once all participants have been informed and given a possibility to opt out. Already such a decision can lead to stigmatization of an individual in a closed society. At a later date, if a new cure has been discovered, this cure may not reach non-participating individuals who may then feel discriminated against.

Problems faced by biobanks are the same problems which were discussed when genetic tests became prevalent – whether the results of these tests can be used to discriminate against persons who have received “abnormal” results by denying them employment, insurance etc., or to stigmatize them by marking them as different from some accepted standard. The cases of discrimination based on genetic tests, though not common, highlight the existence of risks that should not be underestimated. Sometimes such discrimination is due to a misunderstanding of the test results, e.g. in cases where a person is carrier of a recessive mutated allele (and thus in no way ill) or an asymptomatic carrier of a gene mutation which does not cause disease in 100% of the cases. An illustrative example of erroneous belief that everything can be found in the genome, is that of medical examiners demanding that the DNA of murderers should be analysed so that some unique sequence responsible for their behaviour could be identified. The frightening fact is that while we all are 99.9 % similar, each one of us is also unique. However, analysis of a single murderer’s DNA cannot be used to accuse persons who happen to share some alleles with the murderer, while such alleles actually have nothing to do with criminal tendencies. A lot more education is needed to prevent such accusations that could result in serious stigmatization of innocent people.

It should be emphasized, however, that genetic testing is only an extension of the more traditional information, such as illnesses in the family and information from laboratory tests that one has to provide when applying for insurance. Although genetic testing has in many cases

more precise predictive power than genealogical information and medical records, its role is still limited without information on the life style and environmental exposure of the individual.

Whole-genome analysis of biobanked samples is becoming increasingly common. This increases the number of incidental findings which may be of medical relevance to the individual. Should the donor be recontacted in such cases? This is seen as a very serious problem, as this is not necessarily expected by the donor, and moreover the analyses are not performed in a typical diagnostic setting. Recently a National Institutes of Health Committee indicated that biobanks should share information about what is called “incidental findings” if the research results could have medical consequences for the donor. This is not easy – it means recontacting people who may not previously have expressed consent for being recontacted in such a situation. Moreover, this recontacting may entail information which can be considered as stigmatizing a given person and provide him/her with information which would have to be disclosed to insurers and/or employers, leading to possible discrimination. In the future, new IT solutions enabling dynamic consent are likely to facilitate recontacting of the donors in questions pertaining to new consent and communicating incidental findings to the donor or his/her medical provider.

Biobanking and genetic research on indigenous populations is also a sensitive issue. One of the concerns is that the benefits from such research may not reach the community which is being studied. Special care should be taken to respect such concerns and the health needs of participating populations. In some cases, e.g. in Australia, this has created a barrier preventing genetic research, which can also be viewed as discrimination. In North America some web pages run by indigenous populations encourage them to stay away from modern genetic testing and stick to their traditional ways of life. There are, however, also positive examples of studying indigenous people together with majority population. The Northern Finland Birth Cohort of 1966 covers 93.6 % of all babies born in 1966 in the northern half of Finland and has been followed since then at 10-year intervals. This cohort covers also the indigenous Lapp/Saame population and there has been essentially no discussion of discrimination or stigmatization.

5.1.3 Courses of Reflection and Action

Two fundamental problems connected with biobanks and the risk of discrimination and stigmatization are the improper protection of the stored samples and the near-impossibility of preventing of some data from being accessed, and the unresolved problem of incidental findings. A very recent recommendation (March 2013) by the American College of Medical Genetics and Genomics has stated that patients undergoing genomic sequencing in clinical settings should be informed about the results concerning 57 genes which could lead to disease in the future *even if they do not want the information*. Moreover, this is also to be applied to minors, which is in contrast to the commonly accepted ideas, which has found its expression in bioethical declarations, that there is a right not to know, and moreover this right especially applies to minors, who should not be tested for diseases that they may potentially have as adults. These recommendations have been strongly criticized. Both European and Canadian approaches in biobank settings have been to give the individual the right not to know. Time will show what the future will bring. For example, when genetic susceptibility to side effects of drugs become better known, at least the doctor must have access to such data before giving the patient a potentially hazardous drug.

A positive example of successful use of biobanks and genetic testing without discrimination or stigmatization comes from a country consisting of several islands. In this population of 49,000 some genetic diseases are up to 100 times more prevalent than elsewhere. One of them is a hereditary disease called carnitine transporter deficiency (CTD), which has caused sudden

death in young adults. In 2009, the country launched a public effort to identify people afflicted with CTD. In 18 months, almost 30,000 people, 62% of the population, were examined and CTD was diagnosed in 140 individuals. As the disease can be treated with high doses of carnitine, the health benefits were obvious to everyone. The country also established in June 2006 a Genetic Biobank and utilized it in conjunction with medical and genealogical data to support research projects aimed at discovering the relationship between genetic background, environmental influences and disease onset and progression.

Data collected from national carrier screening programmes raise a distinct set of problems, especially if they are compulsory. These data are very sensitive and have to be managed carefully in order not to stigmatize individuals who are carriers of genes responsible for certain diseases. Though no evidence of stigmatization has been found in some carefully analysed carrier programmes, this is always a possibility and such programmes and the sample banks require very careful analysis.

As molecular analysis of biobanked human samples is becoming increasingly important for modern medical practice and research, and genetic testing has become accessible to lay people, there is a burning need to educate individuals and populations how to interpret the results of genetic analyses, including incidental findings. In this respect, educational programmes should be put in place by governments and medical professionals to inform citizens about biobanking, new molecular classification (stratification) of diseases and subsequent development of targeted therapies, i.e. personalized health care. Genetic counselling must be made available to complement educational programs in order to prevent stigmatization of individuals carrying gene alleles causing or predisposing to disease. Similarly, legislative measures should be put in place to prevent discrimination based on genetic testing when seeking employment or health/life insurance. With respect to this goal, the role of the media in disseminating knowledge and fostering the awareness of the new challenges to address is also a fundamental one.

5.2 Nanotechnology

5.2.1 Latest Developments in the Field

Nanotechnology is a broad umbrella term that encompasses a wide range of relatively recent, intensely multidisciplinary, innovative research efforts that involve manipulating matter at the atomic and molecular scale. It can be defined as the study, design, creation, synthesis, manipulation, and application of functional materials, devices, and systems through control of matter at the nanometer scale (1–100 nanometers, one nanometer being equal to 1×10^{-9} of a meter), and the exploitation of novel phenomena and properties of matter that usually appear at that scale. The convergence of a vast array of sub-disciplines greatly complicates demarcating the scope and reach of nanotechnology.

Nanotechnology will probably have a considerable impact on many areas of human endeavour, particularly on energy storage, production, and conversion, water treatment and remediation, food and agriculture enhancement, diagnosis and treatment of disease, manufacturing, international trade, labour markets, the workplace, systems of communication, defense, international relations, civil liberties, and perhaps even the definitions of “life” and “human”. Such wide influence leads to concerns over the ethical, economic, environmental, legal and social issues that could result from advances in nanotechnology (usually abbreviated as NE3LS).

Nanotechnology can provide low- and middle-income countries (LMICs) with clean, affordable, and reliable ways to harness renewable resources, averting recurrent energy crises, dependence on fossil fuels, and environmental degradation brought about by the depletion of oil and coal. It also promises solutions for energy generation and storage, water treatment, and air pollution remediation. Advances in nanotechnology can be used to create inexpensive, easily transportable, and easily cleanable water treatment. Nanoapplications and nanodevices can be developed for cheap, easy to use, highly sensitive and specific, robust, portable, handheld point-of-care diagnostic kits. Nanoparticle systems have also been created for use in medical imaging. Nanodevices based on nanotubes and nanoparticles have been designed to monitor *in situ* the concentrations of physiological variables such as glucose, carbon dioxide, and cholesterol. Novel delivery systems for the slow and targeted release of drugs and vaccines, with desirable features such as thermostability, single dose application, and needle-free use, can help increase shelf life and reduce both required dosages and transportation costs. Inexpensive agricultural applications of nanotechnology such as nanomaterials designed for the slow release and efficient dosage of fertilizers for plants and of nutrients and drugs for livestock can help decrease malnutrition, and thus childhood mortality, by increasing soil fertility and crop productivity, especially in rural regions of the developing world.

It is expected that nanotechnology will be of great significance to the more than five billion people living in the developing world, and thus this population is the focus of this section. Nanotechnologies promise to improve markedly the quality of life of the world's poor, but they also open the doors for stigmatization, discrimination, and marginalization of already vulnerable populations.

5.2.2 Discrimination and Stigmatization Risks

The potential risks of discrimination and stigmatization as a result of advances in nanotechnology, if they were to occur as the field advances, are most likely to be felt by the poor, the unemployed, and those subjected to inequitable power relationships. In contrast to the rich and powerful, these segments of the population are already subject to varying degrees of limitations in human dignity, to an inability to exercise their full human rights as defined by the UN Declaration of Human Rights, and to a reduction of their freedom to gain access to global and national public goods and to exercise choice on matters affecting their lives. The main question regarding nanotechnologies is whether they will remedy or exacerbate the realities of the underprivileged, the powerless, and the vulnerable.

This section addresses the proximate and reasonably down-to-earth instances in which advances in nanotechnology may lead to discrimination and stigmatization of individuals or communities, touching only briefly on the more exaggerated utopic, apocalyptic, and speculative scenarios related to very hypothetical ramifications of nanotechnologies that may even prove to be impossible to develop.

Unequal access to nanotechnologies, along with decreased opportunities and resources for research, development, and innovation (RDI) in this field, could precipitate a "nano-divide" both among countries and among communities, exacerbating the already marked resource and power disparities between the rich and the poor, and further increasing the vulnerability of a large majority of the human population to poverty, disease, inequities, and exploitation. The current technological gap between rich and poor countries likely will extend to nanotechnologies, a process that will further concentrate wealth and power in even fewer hands. This may happen because, while several low and middle income countries (LMICs) are actively involved in RDI of applications of nanotechnology that address their most pressing needs, most nanotechnology activity still takes place in the wealthy, industrialized world.

Dominant individuals, groups, or nations could ignore marginalized populations and take advantage of inadequate or nonexistent regulations to advance their interests. Most LMICs have not yet caught up and might not even have the chance to do so before all useful knowledge is locked up in overly aggressive patents owned by companies in the rich world. Most existing patents and patent applications related to nanotechnology originate in high-income countries (HICs) and are concentrated in a few universities and multinational corporations. About 90 percent of the total patent share in health-related nanoproducts and nanoapplications is held by less than 10 countries, with the vast majority being controlled by the private sector and by companies, not individuals. Future patents related to the use of nanotechnology in health care will likely focus on medical conditions common in the industrialized world at the expense of neglected diseases prevalent in LMICs.

If the worst-case scenario were to occur then poverty, unemployment and powerlessness would be exacerbated, with a concomitant erosion of human dignity, rights and freedoms. The consequence would be an increase in discrimination and stigmatization of the poor by the rich and powerful. But even if nanotechnology RDI in LMICs took off, the benefits might not be equally distributed and inequities could worsen within and among nations.

The lack of advanced education and sophisticated skills in science, technology, engineering, and mathematics (STEM), along with a dearth of highly trained lawyers, patent officers, policy experts, and other decision-makers with solid and up-to-date knowledge about nanotechnology, may exclude a substantial proportion of the world's population from the benefits of nanotechnology. The unfortunate shortage of women in mathematics, engineering, and the physical sciences could extend to areas of nanotechnology, hindering women from participating and benefiting from any advances brought on by nanotechnology, increasing discrimination against women and stigmatizing them further by characterizing them as technologically less adept than men. As English is the *lingua* franca of science and technology, marginalization of non-English speaking individuals could also worsen.

The potential threats of nanomaterials on the environment, on living organisms and on human health have not been completely determined. Matter at the nanoscale tends to exhibit unique properties that may lead to unusual toxic effects that are considerably different from those seen at larger scales. These characteristics of nanomaterials also complicate their removal from air, water, and soil. It will be tempting for the wealthy and powerful to disregard the environmental concerns of less fortunate societies with weak regulatory regimes, and the latter may become dumping grounds for unwanted, low-quality, or potentially toxic nanomaterials and nanoproducts.

The convergence of nanotechnology, biotechnology, genomics, other biomedical sciences, information technology and the cognitive sciences (abbreviated as NBIC), may precipitate a redefinition of the concepts of *normalcy, disability, health, and disease*, and may challenge the very concept of human dignity. At the same time, the increasing miniaturization and effectiveness of inexpensive surveillance through nanoapplications and nanodevices may lead powerful individuals, governments, and corporations to use wider and highly intrusive methods of gathering data and controlling populations, with the potential to severely erode people's privacy, confidentiality, human rights, and well-being. Such "nanopanopticism" could critically endanger civil liberties and open the door to discrimination.

5.2.3 Courses of Reflection and Action

Nanotechnology is both young as a discipline and yet moving so rapidly that there is an urgent need to address its potential for increasing poverty, eroding human dignity, and reducing freedoms; these are elements associated with the risk of discrimination and stigmatization. The

possible hazardous impact on human health and the environment must also be dealt with. Seven strategies are proposed to reduce the likelihood and magnitude of discrimination and stigmatization as a result of the developments of nanotechnology:

1. It is imperative to examine the ethical, economic, environmental, legal and social implications of nanotechnology (NE3LS), to view the developments in this field with a critical but balanced eye, to work with scientists, and to avoid unsophisticated, shallow, and unrealistic scenarios. Given the similarities between these issues and those of previous technologies, and considering the convergence of NBIC, a specific field of "nanoethics" may not be needed.
2. Discussions about NE3LS must address realistic, concrete, and scientifically-based challenges that are relevant to discrimination and stigmatization such as who would be at risk, who would be responsible for monitoring the discriminatory or stigmatizing consequences of the development of nanotechnologies, how these repercussions would impact particular populations, and what preventive or remedial action needs to be taken.
3. Effective, objective, ongoing, fair and respectful public engagement strategies based upon trust, transparency and openness are essential to make people aware of what nanotechnology is and where it is going, and to involve the general public in genuine opportunities for multi-way deliberation and dialogue that carefully examines the benefits and risks of nanotechnology. All relevant stakeholders need to have a say at all stages of the development of nanotechnology and of its practical applications. It is necessary to build and maintain trust by listening to and acknowledging the expectations, fears and concerns of specific populations in order to address issues of apprehension and misgivings about the "other" that usually lead to discrimination and stigmatization. Perceptions about nanotechnology shape the public's reaction to developments in this field, regardless of how much they diverge from reality. Changing perceptions is very difficult and does not depend simply on presenting facts.
4. Nanotechnologies must be adapted to the particular contexts in which they will be applied. For LMICs, this is an opportunity to tackle the emerging nano-divide by designing, developing, producing, and marketing their own appropriate, affordable and accessible nanotechnology products and applications to solve their most pressing developmental needs. The developing world must identify priorities, resources, capabilities, limitations, potential niche areas and opportunities for strategic engagement with nanotechnology. Diasporas, the communities from LMICs who left home to attend school or find better jobs and who currently work in industrialized nations in academia, research, or industry might be a very useful resource. The success of these strategies would counter the strong prejudice against developing countries by providing evidence that their populations are more than capable of facing developmental challenges through advanced technologies.
5. Extant laws and regulations must be examined to determine whether they can cope with emerging nanotechnologies. If new laws and regulations are needed, they must take into account the potential for discrimination and stigmatization resulting from nanotechnology RDI. A special focus is needed on nano-pharmaceuticals and medical products, building also on existing instruments such as the guidelines by the International Conference on Harmonization.
6. All countries, especially in the developing world, should strive to provide a broad and rigorous interdisciplinary education at all academic levels that prepares individuals for knowledge-based economies and that includes both STEM fields and humanistic disciplines. Serious efforts are needed especially to recruit and prepare women in

STEM-related areas. A specific challenge will be to decrease stigmatization and marginalization by bridging language barriers resulting from highly-specialized terminology and from the use of English as an exclusive academic lingua franca.

7. Nanodiplomacy, the skillful collaboration between nations with the aim of taking advantage of the opportunities offered by nanotechnology to address developmental needs, may be required to prevent discrimination and stigmatization of individuals or populations resulting from advances in this field. The UN, through UNESCO, should ensure that discussions about NE3LS issues and about the potential benefits and risks of nanotechnology specifically address concerns related to discrimination, stigmatization, and marginalization to encourage the use of this promising technology wave to improve the quality of life of human beings worldwide.

Nanotechnology has great potential for improving quality of life through advances in many areas including energy storage, production, and conversion; agriculture productivity enhancement and food processing; water treatment and remediation; prevention, diagnosis, and treatment of human disease; environmental remediation; transportation, and communication. But nanotechnology also presents risks that could potentially result in discrimination, stigmatization, and marginalization of large numbers of individuals worldwide, particularly of the poorest and most vulnerable. The most serious of these challenges are the creation of a nano-divide that widens the gap between the rich and the poor, and the failure to consider realistic health and environmental risks. In this respect, seven strategies are proposed to address these and other risks.

5.3 Neuroscience

5.3.1 Latest Developments in the Field

Persons with mental illness have long been objects of fear and misunderstanding. Although humane attitudes toward the mentally ill are in formation, progress has been too slow. Schizophrenia, depression, Alzheimer's disease, autism and Asperger's disease are only a few of the conditions that exact a high toll on those who suffer from them and for their families. The appreciation of mental illness as a set of brain-based disorders rather than a form of moral weakness might alter the landscape of treatment for these vulnerable persons, but it also brings its own risks of discrimination and stigmatization. In this perspective, what we are called on to address are the consequences of a different, more effective approach to specific kinds of suffering, which appear to be strictly interwoven with well-known, persistent situations of marginalization and lack of respect for human dignity. Needless to say, this is a fundamental task to perform. Beyond that, however, we start being confronted with new, emerging risks, which may be looked at as the possible dark side of the unprecedented opportunities that neuroscience is making available.

Neuroscience may be the fastest growing field of human knowledge. In its "Scientific Vision," the Society for Neuroscience (SfN), the world's largest organization of scientists and physicians devoted to advancing understanding of the brain and nervous system, describes neuroscience as:

> "the entire range of scientific research endeavors aimed at understanding the nervous system and translating this knowledge to the treatment and prevention of nervous system disorders." (SfN, 2012)

With a clear strategic plan and scientific vision, SfN "fosters the broad interdisciplinarity of the field that uses multiple approaches (e.g., genetic, molecular, cellular, anatomical, neurophysiological, system, comparative, evolutionary, computational, and behavioral) to study the nervous system of organisms ranging from invertebrates to humans across various stages of development, maturation, and aging".

This description assumes that the main objective of neuroscience is to help people with neurologic disorders. But there will be further bioethical problems with this new knowledge, such as how to distinguish between neurologic disorders and deviations of "normality" with no disabling impact for the individual. Further, all these fields of investigation have so far been mainly biological; the social sciences are thus far secondary participants in discussions about the association between biology and social education.

5.3.2 Discrimination and Stigmatization Risks

Discrimination and stigmatization persist in the entire world and are independent of science. But science, and especially new sciences as genetics and neurosciences, may enhance or mitigate this situation. More specifically: discrimination and stigmatization are products of social relationships based on the rejection of the different "other". Two questions to be posed are as follows:

1. How may neuroscience enable or enhance the risks of existing discrimination/stigmatization and enable new risks?
2. How may neuroscience help to understand and perhaps mitigate the effects of discrimination/stigmatization?

The problem of neuroscience enabling or enhancing the risks of discrimination / stigmatization has much in common with other risks associated with personal medical information. Many worry today about privacy with regard to genetic data, for example. Except for certain single-gene disorders one's individual genome tells hardly anything about one's risk of a particular disease, nonetheless genomic information may be used in a discriminatory fashion. Of course, modern genetic analysis is not required for genetic discrimination to occur. Information about family history has led to illicit inferences about that individual's personal risk factors or social destiny, sometimes with catastrophic results, as in the case of 20th century eugenic sterilization programs.

On a rough analogy with genetic discrimination, the most obvious source of discrimination from neuroscience seems to be the misinterpretation of data from neuroimaging. Images that suggest some non-standard or exceptional neuroanatomy could be taken as more informative about, say, intelligence or personality than they really are. But this seems to be a far lower social risk than the problems associated with genomics because genomic analysis is far easier and (so far) cheaper to perform than neuroimaging studies. However, one may certainly imagine cases in which a medical record includes brain imaging that would be highly prejudicial to the patient if the patient's confidentiality was not respected. (This problem is distinct from, but related to, the dilemmas that ensue from incidental findings in the course of neuroimaging studies utilizing presumptively healthy, normal subjects, findings that may have medical implications for the subjects.)

A somewhat more plausible policy problem would arise if large numbers of school children were referred for brain imaging upon suspicion of some brain-based behavioral or personality disorder. Already neuroimaging has been used in legal cases to assist in retrospective arguments about the defects that might have helped lead an individual to engage in a violent crime. If prospective screening were ever a matter of policy there would naturally be a period

during which even experts disagreed about the likelihood that such information would be diagnostic with regard to a child's future psychological development. Those children who were "false positives" would surely be at high risk for stigmatization. Evidence seems to indicate that even children from well-off families could be affected by discrimination and stigmatization if the parents' decisions were taken according to information deriving from the children's neurological structures.

As population-based neuroscience data continues to be collected there is a more worrisome potential problem of stigmatization with regard to racial or ethnic groups. The history of debates about the relationship between intelligence and race is well known. One recent study concludes that African-Americans have on average one standard deviation less cerebral volume than European Americans. Scientific discussions about the interpretation of these findings must be done on the basis of ethical values to prevent discriminatory or stigmatizing interpretations, as the potential for discrimination facilitated by large datasets from neuroscience is not hard to imagine.

Scientists are responsible for analyzing the findings of neuroscience and presenting them to the public, and must proceed according to bioethical values of human rights. Existing bioethics committees, social workers and specialists in scientific communications have to participate in the debates about these findings. The transparency of investigations in neurosciences (from the sources of financing to the results) and their discussion by the international scientific community is very important to mitigate the risks of domination and discrimination.

Yet neuroscience may help to understand and perhaps mitigate the risks of discrimination and stigmatization of individuals. That is, it may do so if the human personality, including personal biases, is represented in certain activities of the brain and central nervous system to which neuroscience gives us access. However, there is deep disagreement about the precision of our ability to represent these underlying somatic features.

There is evidence that such abstract attitudes as those having to do with moral decision-making can be measured and modified in the laboratory through a combination of neuroimaging and neuromodulation.

Neuroscience studies have revealed a "same-face advantage" when small groups of black and white subjects were exposed to pictures of unfamiliar black and white faces. Both black and white subjects were better at recognizing same-race faces, though the effect was significant only for the white subjects. These results were correlated with activation of a part of the brain called the fusiform gyrus. Although it is far too early to be sure, perhaps the results of studies like these may someday provide the key to managing and modifying discrimination and stigmatization. Then we face a series of supremely difficult questions: Should we attempt to engage in brain modification of offenders? Unanswered questions are: what proportion of these behavioral findings is genetically or ontologically determined and what is the importance of culture and education for the personality of each individual?

In fact societies are imprisoning violent offenders who cannot be classified as mentally disturbed; will investigations in neuroscience create the opportunities to alter this conduct through the modification of some fields of their brain? Who would decide which values are to be the standards for modification? Presumably, Enlightenment values of the widest possible range of respect for human beings would be the ones enforced?

Another way, like using neuroscience on a population scale, cannot be supported if there is an agreement with the values of these declarations. Electing another way would mean that any system that had the power to engage in such practices might not choose to act in accordance with Enlightenment principles. One can hardly fail to note the prescience of this passage from

George Orwell's *Nineteen Eighty-Four*: "The two aims of the Party are to conquer the whole surface of the earth and to extinguish once and for all the possibility of independent thought. There are therefore two great problems which the Party is concerned to solve. One is how to discover, against his will, what another human being is thinking, and the other is how to kill several hundred million people in a few seconds without giving warning beforehand."

Therefore, the greatest risk of neuroscience with regard to discrimination and stigmatization may not be that we will learn too little but that we will learn too much.

5.3.3 Courses of Reflection and Action

How, then, should the course of reflection on these questions begin? First, there should be a reassurance that the application of neurotechnologies is in its infancy, and many of the most disconcerting elements will never be practicable. Therefore there is time for reflection. Second, some applications that are both promising and perilous will certainly emerge, though it is hard to say with confidence which ones; it would be worth applying the precautionary principle as strictly as possible in order to guarantee the right to life, quality of life, decent environment, freedom and equality of people. Third, every effort should be made to encourage ongoing forums in the field of neuroethics to incorporate discrimination and stigmatization into their range of concerns. Fourth, the Society for Neuroscience and the International Neuroethics Society should hold special sessions on this topic. Fifth, governmental and non-governmental agencies should support relevant ethical discussions and projects, and where suitable incorporate these questions into their review processes for work on emerging technologies. Sixth, member states and international human rights organizations should consider whether current principles, laws and standards are sufficiently specific to address discrimination and stigmatization in relation to neuroscience.

Persons training for careers in neuroscience should be exposed to core principles of science ethics (including but not limited to respect for persons and minimization of harm), the responsible conduct of research, and the more general social responsibilities of scientists for the outcome, dissemination and communication of research results and their global impact. Governments, professional organizations, educational institutions, and international sources should all be involved in the development of codes and guidelines in ways that are relevant to neuroscience. Efforts should be made to enlist in these discussions organizations that advocate for the interests and protection of vulnerable persons and groups.

6 CONCLUSION

Among UNESCO's overarching objectives is that of addressing emerging social and ethical challenges. Its mission is to contribute to sustainable development, to be accomplished through dialogue between cultures to achieve the global vision of mutual respect. Mutual respect requires that ethically unjustifiable discrimination and stigmatization not be tolerated.~~,~~ Sustainable development demands that emerging social and ethical issues be identified, so far as is possible, in advance of their disruptive consequences, and if they are persistent they must be clearly stated and efforts to resolve them must be redoubled.

In this report, a number of persistent and emerging sources of unethical discrimination and stigmatization have been identified and assessed. These do not represent all of the challenges and opportunities for sustainable development posed by medicine and the life sciences – a field of human endeavor that, it must be repeated, has in general vastly improved the conditions of human life -- nor even all those that involve discrimination and stigmatization. But they are a reasonable sample that calls on the energy and wisdom of the international community and

well-meaning persons everywhere. Moreover, the selected topics and examples provided are meant to raise awareness leading to the establishment of brainstorming groups, discussion fora, educational programmes and policies aimed at countering discrimination and stigmatization.

BIBLIOGRAPHY

Asian Task Force on Organ Trafficking (2007) *Recommendations on the Prohibition, Prevention and Elimination of Organ Trafficking in Asia*. Available at http://www.jointcentreforbioethics.ca/publications/documents/Asian%20Task%20Force%20on%20%20organ%20trafficking%20.pdf

CoE (1997) *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, Strasbourg: Council of Europe. Available at http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm

CoE (2002) *Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin*, Strasbourg: Council of Europe. Available at http://conventions.coe.int/Treaty/en/Treaties/Html/186.htm

The Declaration of Istanbul on Organ Trafficking and Transplant Tourism (2008) Available at http://www.declarationofistanbul.org/

EC (2012) *Biobanks for Europe: A Challenge for Governance*, Brussels: European Commission. Available at http://www.coe.int/t/dg3/healthbioethic/Activities/10_Biobanks/biobanks_for_Europe.pdf

GODT (2010) *Organ Donation and Transplantation Activities 2010*, Online: Global Observatory on Donation and Transplantation (WHO-ONT Collaboration). Available at http://issuu.com/o-n-t/docs/2010adgodt?mode=window&pageNumber=1&layout=http://publicaciones.ont.es/issuu/godt/layout.xml

London Declaration on Neglected Tropical Deseases. Available at: http://unitingtocombatntds.org/downloads/press/ntd_event_london_declaration_on_ntds.pdf

OECD (2009) *OECD Guidelines on Human Biobanks and Genetic Research Databases*, Paris: Organisation for Economic Co-operation and Development. Available at http://www.oecd.org/sti/biotech/44054609.pdf

SfN (2012) *Strategic Plan*, Washington D.C.: Society for Neuroscience. Available at http://www.sfn.org/about/mission-and-strategic-plan/strategic-plan

UN (1948) *The Universal Declaration on Human Rights*, New York: United Nations. Available at http://www.un.org/en/documents/udhr/index.shtml

UN (1965) *International Convention on the Elimination of All Forms of Racial Discrimination*, New York: United Nations. Available at http://www.ohchr.org/Documents/ProfessionalInterest/cerd.pdf

UN (1966a) International Covenant on Civil and Political Rights, New York: United Nations. Available at http://www.ohchr.org/Documents/ProfessionalInterest/ccpr.pdf

UN (1966b) *International Covenant on Economic, Social and Cultural Rights*, New York: United Nations. Available at http://www.ohchr.org/Documents/ProfessionalInterest/cescr.pdf

UN (1979) *Convention on the Elimination of All Forms of Discrimination against Women*, New York: United Nations. Available at http://www.ohchr.org/Documents/ProfessionalInterest/cedaw.pdf

UN (2000a) *Optional protocols to the Convention on the Rights of the Child on the involvement of children in armed conflict and on the sale of children, child prostitution and child pornography*, General Assembly Resolution A/RES/54/263 of 25 May 2000, New York: United Nations. Available at http://www.un-documents.net/a54r263.htm

UN (2000b) *Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, Supplementing the United Nations Convention Against Transnational Organized Crime*, New York: United Nations. Available at http://www.unodc.org/documents/treaties/UNTOC/Publications/TOC%20Convention/TOCebook-e.pdf

UN (2000c) *United Nations Convention Against Transnational Crime*, New York: United Nations. Available at http://www.unodc.org/documents/treaties/UNTOC/Publications/TOC%20Convention/TOCebook-e.pdf

UN (2001) *Declaration of Commitment on HIV/AIDS*, New York: United Nations. Available at http://www.un.org/ga/aids/docs/aress262.pdf

UN (2010) *The Millennium Development Goals Report 2010*, New York: United Nations. Available at http://www.un.org/millenniumgoals/pdf/MDG%20Report%202010%20En%20r15%20-low%20res%2020100615%20-.pdf

UNAIDS (2011) *Global AIDS Response Progress Reporting 2012*, Geneva: Joint United Nations Programme on HIV/AIDS. Available at http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/JC2215_Global_AIDS_Response_Progress_Reporting_en.pdf

UNESCO (1997) *Universal Declaration on the Human Genome and Human Rights*, Paris: United Nations Educational, Scientific and Cultural Organization. Available at http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html

UNESCO (2003) *International Declaration on Human Genetic Data*, Paris: United Nations Educational, Scientific and Cultural Organization. Available at http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html

UNESCO (2005) *Universal Declaration on Bioethics and Human Rights*, Paris: United Nations Educational, Scientific and Cultural Organization. Available at http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html

UNESCO (2008) *Report of the International Bioethics Committee of UNESCO (IBC) on Consent*, Paris: United Nations Educational, Scientific and Cultural Organization. Available at http://unesdoc.unesco.org/images/0017/001781/178124e.pdf

UNESCO (2010) *Report of the International Bioethics Committee of UNESCO (IBC) on Social Responsibility and Health*, Paris: United Nations Educational, Scientific and Cultural Organization. Available at http://unesdoc.unesco.org/images/0018/001878/187899E.pdf

UNESCO (2013) *The Principle of Respect for Human Vulnerability and Personal Integrity: Report of the International Bioethics Committee of UNESCO (IBC)*, Paris: United Nations Educational, Scientific and Cultural Organization. Available at http://unesdoc.unesco.org/images/0021/002194/219494E.pdf

WFP (2010) *Fighting Hunger Worldwide: Annual Report 2010*, Rome: World Food Programme. Available at http://home.wfp.org/stellent/groups/public/documents/communications/wfp220666.pdf

WHO (2009) *Neglected Tropical Diseases, Hidden Successes, Emerging Opportunities*, WHO/HTM/NTD/2009.2, ISBN 978-92-4-159870-5. Geneva: World Health Organization. Available at http://whqlibdoc.who.int/publications/2009/9789241598705_eng.pdf

WHO (2010a) *WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation*, Geneva: World Health Organization. Available at http://www.who.int/transplantation/en/

WHO (2010b) *Working to overcome the global impact of neglected tropical diseases: First WHO report on neglected tropical diseases.* Available at http://whqlibdoc.who.int/publications/2010/9789241564090_eng.pdf

WHO (2012) *Accelerating work to overcome the global impact of neglected tropical diseases. A roadmap for implementation. Available at* http://whqlibdoc.who.int/hq/2012/WHO_HTM_NTD_2012.1_eng.pdf

WHO (27 May 2013) *Neglected Tropical Diseases*. Sixty-sixth World Health Assembly, WHA66.12, Agenda Item 16.2. Available at http://www.who.int/neglected_diseases/mediacentre/WHA_66.12_Eng.pdf

WHO TDR (2012) *Global Report for Research on Infectious Diseases of Poverty.* Available at www.who.int/tdr/publications/global_report/en/

WHO; UNAIDS and UNICEF (2009) *Towards Universal Access - Scaling up priority HIV/AIDS interventions in the health sector: Progress Report*, Geneva: World Health Organization. Available at http://www.who.int/hiv/pub/2010progressreport/report/en/index.html

World Bank (2011) *World Bank Annual Report 2011*, Washington, DC: World Bank. Available at http://web.worldbank.org/WBSITE/EXTERNAL/EXTABOUTUS/EXTANNREP/EXTANNREP2011/0,,contentMDK:22969490~menuPK:8121330~pagePK:64168427~piPK:64168435~theSitePK:8070617,00.html

WTO (2001) *Doha Declaration on the TRIPS Agreement and Public Health*, Geneva: World Trade Organization. Available at http://www.wto.org/english/thewto_e/minist_e/min01_e/mindecl_trips_e.htm