



Comment/Essay on “Technology, intervention and control of individuals. Human Rights Challenges.”

Abstract

The Essay on “Technology, intervention and control of individuals. Human Rights Challenges” sums up the speech held by professor Dominique Thouvenin during the International Conference organized by the Committee on Bioethics of the Council of Europe. It is a reflection on the convergences between neurotechnology, nanotechnology, information technologies and cognitive sciences (NBIC), termed “emerging technologies”.

We will discuss the uses that can be made of NBICs technologies in terms of medical and non-medical scope. In other words, uses that are relevant in the healthcare procedure but also outside the medical field.

Thus, one of the main problems that we deal with in this analysis is a definitional one: when the use of a certain type of medical treatment can be confirmed as therapeutical when it is no longer therapeutic.

In order to briefly discuss human enhancement and genetic susceptibility and the problems related with the legislation and its limits in these issues, our source will be also the document “Converging Technologies for Improving Human Performance nanotechnology, biotechnology, information technology and cognitive science” Edited by Mihail C. Roco and William Sims Bainbridge of the National Science Foundation.

In relation to the essay it will be useful considering both the Oviedo convention and the European convention on Human rights.

Essay

Converging technologies are the result of innovation both scientific and technological. Today technology is exponentially growing and is having long-terms effects in key areas of human activity, ranging from therapeutic interventions to the non-medical areas such as learning, working and so on.



In the last century new concepts and new researches have been developed, with outcomes considered unexpected until few years ago. And, in the current century, the new so called “Emerging Technologies” as nanotechnology, biotechnology, information technology and cognitive science (that from now on we will simplify as NBIC) are now converging. Also, due to the technological improvement that are achieving in various fields of life, NBIC needs a proper attention; converging technologies are running on the evolution of a hierarchical architecture for integrating natural and human sciences across many perspectives, but has each individual the right to use new knowledges and technologies in order to achieve personal goals? And to what extent?

The importance of NBIC technologies lies in their ability to promote a new concept of “cure and healthcare”. Thanks to NBIC converging technologies not only can ill people (in the common view of illness) be cured, but also different categories of individuals can keep themselves healthy as medicine allows adoption of preventive measures even though there is no diagnosis of illness.

Considering the differences of treatment and approaches between the medical and non- medical scope of these new technologies, we should divide the two branches.

Firstly, we should take in account an ill person, which can suffer from a chronic illness that needs a constant supervision (the author takes in account the case of the monitoring of a diabetic patient) or an invasive procedure (which can be the case of the Deep Brain Stimulation) that needs specific medical competences. In these cases, the person considers himself ill and decides to consult a doctor in order to receive a therapeutic advice. It is necessary for the medical procedure that the patient has a therapeutic education which requires *in primis* information related to the procedure, then comprehension of treatment which will be administered to the person in order to give an appropriate consent for the intervention and understand its consequences and risks. Thus, the primary aim is to give the patient the most complete skills about the intervention and the risks. However, at the same time, it is not auspicious to overwhelm the patients with excessive information which are in some cases only deleterious for the therapy and could put the patient in a risky position (i.e. the patient can be worried about the negative results that a certain therapy can cause him even though the risks are not very likely and the therapy could be very successful for him/her).

Secondly, we have the healthy, outside the medical sphere in a non- medical context; this type of individual can decide to take part in the research due to curiosity, a personal interest or to be helpful. In those cases, the digital world gets in contact with the biological body in order to promote the prevention of diseases or to reduce the healthcare costs. We can consider two cases:

The first case considered by professor Thouvenin is the so called “quantified self” (a movement founded in California in 2007). The term refers to a campaign whose aim is to promote wellness



analyzing various lifestyles related activities. This investigation works through a sensor synchronized with a mobile application that tracks the performances of the people who have agreed to use it during their activities; to make this system work it is necessary to record and to monitor a number of variables of people such as nutrition, weight and so on.

The other non-directly medical application that we can consider is the “Gene Therapy” as described in the book by Jeffrey Bonadi (we have some examples and explanation in the document “Converging Technologies for Improving Human Performance nanotechnology, biotechnology, information technology and cognitive science”).

The study of human genome is important under various aspects, it helps improving our understanding of diseases and their process as well as of susceptibility to give genetic disorders or diseases.

In both the abovementioned cases, even though it is clear that the scopes are different (in the first case we are monitoring various lifestyles in order to prevent diseases while in the case of the genome therapy we already know that the mutation is present but we want to eliminate it) rights of the people involved are the same. Indeed, the first relevant interest, covered by the European Convention on Human Rights and by the Convention for the Protection of Individuals of 1981 is to protect “private life”.

Article 8 of the European Convention on Human Rights provides in the first subparagraph that *everyone has the right to respect for his private and family life, his home and his correspondence*. The relevance of private information raises its interest also to prior notification users. The right to protect private life is increasingly becoming very relevant. Indeed, to live in a digital era means that people should pay more attention both to the use by institutions that are managing their data and to the use they consent; i.e. once personal data are trespassed digitally, they are no longer linked to the individual from whom they are derived and not covered anymore by rules on data protection, they can be used for different reasons, can be stored or sold.

On the other hand, in the document “Emerging technologies and Human rights”, the procedures of technologies used for medical reason are, according to the writer, divided under different rules: the first one is referred to in article 4 of the Oviedo Convention and provides that “*any intervention in the field must be carried out in accordance with relevant professional obligations and standards*”; it means that any action or sometimes any specific operation on the patient must be carried out with the proper competence of the doctor (we have already discussed about the duty to inform the patient in order to receive a proper information and give conscious consent). The reason is that in both cases of



entailing invasive procedures and dealing with a chronic illness the rules of information and consent must be respected.

For both medical and non-medical use there is another important matter of discussion: the insurance. Today it is necessary to evaluate the impact that insurances can have on emerging technologies. Due to the constant increasing of chronic illness in Europe plus the high level of health costs, insurance obligations can create new ethical-legal problems: for instance, imagine the costs that people who are not ill but carry a gene mutation, may be asked to pay to insurance companies because of the health related risks. Those people carrying a gene mutation to a multifactorial disease, create a new category of individuals, in between ill and healthy people, the so called “unpatients”. Should unpatients pay as an ill person or should they pay as a non-ill one? The relevance given to the concept of illness is very important also for the differences between preventions, which could be paid by the non-ill person, and the cure of illness, which should not be paid directly from the patient.

Plus, in the end, even though it is not specified in the document of professor Thouvenin, the medical use is quite controversy also with regards to the topic of “human enhancement”. In these cases, we can consider the use of technologies as medical but at the same time we are not dealing with ill people, we are dealing with healthy people that would like to improve themselves with the use of medical technologies. Sometimes they have a predisposition which can be found in genes (as we have already seen) and in other cases the person has only the desire to improve himself, morally or physically. The main difference between the medical scope for ill people and non-ill patients is that the Oviedo Convention is apparently forbidding the genetic therapy for human enhancement, and so, it’s not protecting the interests of healthy patients which would like to medically improve themselves.

How can we develop an adequate legal framework on this topic? How could law specify which are the boundaries between an ill person, an unpatient and a healthy person?

These difficult questions highlight problems related to legal intervention in particular of how to (and if) modify the current legislation.

According to professor Thouvenin the Oviedo Convention should be amended in various articles in order to incorporate use of data deriving from people including row data since right now it is not intended to be applied to non-medical approaches. The human rights and fundamental freedoms, which constitute the basis of general European principles such as equality, solidarity, justice and dignity, ought to inspire the work of those dealing with NBICS technologies outside the medical field. It should be taken into account that technological development and digital systems are reducing the walls between countries and cultures. Today, for instance a lot of informatic operators, with which



European citizens are in contact, are from non-European countries; does this mean that the rights of European citizens are limited? From the ethical point of view but especially from the legal one, it should be found a valid legislation for all the countries unifying technologies and bearing in mind rights of citizens in the first place.