

Haileybury MUN

Research report



Human Rights Council: Committee 1

The question of human rights surrounding neurotechnology

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Introduction

As the world of neuroscience and neurotechnology rapidly advances in refinement, the chance for human rights violations increase dramatically as the possibilities of collecting data and manipulating the brain are quickly becoming reality. A multitude of scientists have been calling out the ethical concerns for the future of neurotechnology including a group of neuroscientist, ethicists, and machine learning experts from the morning side group. However, many experts in multiple professions have recognised the potentially beneficial aspects of neurotechnology as many practical uses could cure formerly incurable diseases or allow prosthetics work the same as a natural limb.

Definitions

Neurotechnology: (1) Technical and computational tool that measure and analyse chemical and electrical signals in the nervous system, be it the brain or nerves in the limbs. These may be used to identify the properties of nervous activity, understand how the brain works, diagnose pathological conditions, or control external devices (neuroprostheses, 'brain machine interfaces').

(2) Technical tools to interact with the nervous system to change its activity, for example to restore sensory input such as with cochlea implants to restore hearing or deep brain stimulation to stop tremor and treat other pathological conditions.

Brain computer/machine interfaces (BCI): The collaboration between the brain and a device (e.g a prosthetic limb or cursor) to control external activity by enabling a direct communication pathway rather than using the body's neuromuscular system.

Deep brain stimulation: The reversible neurosurgical procedure of implanting fine wires into the brain which delivers high frequency stimulation to the targeted area to change some of the brains electrical signals.

Neuroprosthetics: Output neural interfaces, which converts the brain's intentions to external actions

Consent (In relation to IDHGD): Any freely given specific, informed and express agreement of an individual to his or her genetic data being collected, processed, used and stored.

Data linked to an identifiable person: Data that contain information, such as name, birth date and address, by which the person from whom, the data were derived can be identified

Genetic counselling: A procedure to explain the possible implications of the findings of genetic testing or screening, its advantages and risks and where applicable to assist the individual in the long-term handling of the consequences. It takes place before and after genetic testing and screening.

Invasive procedure: Biological sampling using a method involving intrusion into the human body, such as obtaining a blood sample by using a needle and syringe.

Optogenetics: the usage of light to control cells in living tissue, especially neurons.

Human Rights Which Could Possibly Be Violated By Neurotechnology

United Declaration of Human Rights:

Article 4: No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 12: No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, or to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 16:

(1)...

(2) Marriage shall be entered into only with the free and full consent of the intending spouses.

(3)...

Article 18: Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19: Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20:

(1)...

(2) No one may be compelled to belong to an association.

Article 21:

(1)...

(2)...

(3) The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22: Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 29:

(1) Everyone has duties to the community in which alone the free and full development of his personality is possible.

(2)...

(3)...

Article 30: Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

Universal Declaration on the Human Genome and Human Rights (UDHGHR): adopted to prevent the usage and collection of genetic information in ways which would violate the human rights stated above; protects the human genome from improper manipulations that could halt future generations.

International Declaration on Human Genetic Data (IDHGD):

Article 5, Purposes: Human genetic data and human proteomic data may be collected, processed, used and stored only for the purposes of:

- (i) diagnosis and health care, including screening and predictive testing;
- (ii) medical and other scientific research, including epidemiological, especially population-based genetic studies, as well as anthropological or archaeological studies, collectively referred to hereinafter as “medical and scientific research”;
- (iii) forensic medicine and civil, criminal and other legal proceedings, taking into account the provisions of Article 1(c);
- (iv) or any other purpose consistent with the Universal Declaration on the Human Genome and Human Rights and the international law of human rights.

Article 6, Procedure: (a) It is ethically imperative that human genetic data and human proteomic data be collected, processed, used and stored on the basis of transparent and ethically acceptable procedures. States should endeavour to involve society at large in the decision-making process concerning broad policies for the collection, processing, use and storage of human genetic data and human proteomic data and the evaluation of their management, in particular in the case of population based genetic studies. This decision-making process, which may benefit from international experience, should ensure the free expression of various viewpoints.

(b) ...

(c) When the collection, processing, use and storage of human genetic data, human proteomic data or biological samples are carried out in two or more States, the ethics committees in the States concerned, where appropriate, should be consulted and the review of these questions at the appropriate level should be based on the principles set out in this Declaration and on the ethical and legal standards adopted by the States concerned.

(d) It is ethically imperative that clear, balanced, adequate and appropriate information shall be provided to the person whose prior, free, informed and express consent is sought. Such information shall, alongside with providing other necessary details specify the purpose for which human genetic data and human proteomic data are being derived from biological samples, and are used and stored. This information should indicate, if necessary, risks and consequences. This information should also indicate that the person concerned can withdraw his or her consent, without coercion, and this should entail neither a disadvantage nor a penalty for the person concerned

Article 8, Consent: (a) Prior, free, informed and express consent, without inducement by financial or other personal gain, should be obtained for the collection of human genetic data, human proteomic data or biological samples, whether through invasive or non-invasive procedures, and for their subsequent processing, use and storage, whether carried out by public or private institutions. Limitations on this principle of consent should only be prescribed for compelling reasons by domestic law consistent with the international law of human rights.

(b) When, in accordance with domestic law, a person is incapable of giving informed consent, authorization should be obtained from the legal representative, in accordance with domestic law. The legal representative should have regard to the best interest of the person concerned.

(c)...

(d)...

Article 12, Collection of biological samples for forensic medicine or in civil, criminal and other legal proceedings: When human genetic data or human proteomic data are collected for the purposes of forensic medicine or in civil, criminal and other legal proceedings, including parentage testing, the collection of biological samples, in vivo or post-mortem, should be made only in accordance with domestic law consistent with the international law of human rights.

The Benefits

- Deep brain stimulation can be used to treat Parkinson's disease as it is a reversible and 'non-destructive' type of surgery. It is an alternative option to lesioning surgery which is invasive and damages part of the brain. Although it is not a cure, the symptoms of Parkinson's can be controlled. DBS is also being used for OCD and severe depression
- The use of BCIs can allow partially paralysed or fully paralysed patients to use prosthetic limbs as if they were their original limbs
- Neurosurgeon Jocelyn Bloch was able to make 3 men walk again after an accident which left the men paralysed in their by implanting 16 electrodes into the lumbar region of their spinal cord which allowed the men to learn to walk with the targeted electrical stimulation
- Optogenetics allows scientists to control specific neurons and study the relationship between different neurons which could provide a more specific way to treat Parkinson's, depression and schizophrenia

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