RESPONSE TO HUMAN RIGHTS COUNCIL ADVISORY COMMITTEE QUESTIONNAIRE ON "NEUROTECHNOLOGY AND HUMAN RIGHTS"

The O'Neill Institute for National and Global Health Law was established in 2007 with the goal of responding to the need for innovative solutions to the most critical health problems in our global, national and local communities. Located at Georgetown Law in Washington D.C., the O'Neill Institute seeks to contribute to a more vigorous and deeper understanding of the many ways in which law, including human rights, can be used to improve health.

The O'Neill Institute's has different initiatives that drive change by advancing cutting-edge research on global health and the law, and providing solutions to urgent problems facing policymakers, practitioners, and scholars. The "Health and Human Rights Initiative" works to improve health through academic research that focuses on the nexus between health and international human rights law. Its team works closely with local partners focusing on strategic litigation, technical assistance to local and national governments, and capacity building, especially in Latin America.

Ríos-Rivers is a nonprofit organization based in Washington DC that provides strategic support to local and regional organizations in Latin America and the Caribbean that work on reproductive and social justice through strategic lawyering and technical legal work. Ríos-Rivers works closely with the O'Neill Institute's Health and Human Rights Initiative in the provision of technical assistance to local partners.

Below are the responses to the questions that are most relevant to our field of expertise, the nexus between health and international human rights law, in particular the inter-American human rights system. Some related questions are answered jointly.

Impact, opportunities and challenges

4. What human rights will be mostly impacted by the development and use of neurotechnologies? Identify the three rights most impacted and briefly explain why. **5.** What are the biggest challenges and risks that the development, test and use of neurotechnologies pose to human rights?

The proliferation of technologies that can read and/or modify brain activity may jeopardize the enjoyment and exercise of multiple rights and freedoms, such as the right to privacy, freedom and autonomy, political rights, freedom of association, freedom of expression, freedom of assembly, the right to work and the right to education, and equality and non-discrimination.

Below, we briefly develop the reasons why three of these rights could be particularly impacted by the use of neurotechnologies and the main challenges they pose:

- *Right to identity:* the adverse or undesired effects of neurotechnologies can compromise the user's sense of identity in at least two ways. First, by modifying certain relatively stable personality characteristics, such as modulation or manner of speech, political orientation, or behavior. By way of example, side effects associated with deep brain stimulation can include psychosis, hypersexuality, pathological gambling, and mood swings[1] - all issues that have a direct impact on the user's personality. Second, modification neurotechnologies have the potential to influence memory formation, a fundamental component of identity. Through the production of optical stimuli, brain stimulators could introduce artificial memories into the brain, or alter existing ones, generating false memories in the user. Although underdeveloped, the possibility of modifying memory has already been verified in animals.[2]

- *Right to privacy:* the brain contains an extraordinary amount of personal information - "neural data" or "brain data" – that is highly sensitive and closely linked to a person's identity. This is data that reflects an individual's neural activity and therefore contains unique information about his or her physiology, health and mental states[3]. Neurotechnologies have the ability to access all of this information, including subconscious tendencies, biases and other information beyond a person's control, and can even store it for extended periods of time. Although individuals may have an interest in the disclosure of such information (e.g., someone who undergoes an electroencephalogram to learn whether he or she has a

[1] CIB, *Report of the International Bioethics Committee of UNESCO (IBC) on the ethical issues of neurotechnology*, SHS/BIO/IBC-28/2021/3 Rev. (2021); párr. 22; Mayo Clinic, Deep brain stimulation.
[2] Sara Goering et al., "Recommendations for Responsible Development and Application of Neurotechnologies," *Neuroethics* 14, no. 3 (2021).
[3] OCDE, *Recommendation of the Council on Responsible Innovation in Neurotechnology*, OECD/LEGAL/0457, párr. II (2019).

schizoaffective disorder), the possibility of commercial development of neurotechnologies for mass consumption poses the certain risk of unauthorized disclosure or use of neural data.

- *Right to equality and non-discrimination:* the use of neurotechnologies can affect this right in three ways. Firstly, given that they can become key tools to ensure accessibility for people with disabilities and guarantee their inclusion in the community, if equitable distribution and access are not ensured, they could compromise the components of availability and accessibility without discrimination of the right to health,[4] generating and deepening already existing inequalities. Second, because they are developed by humans, there is a risk that neurotechnologies may reflect their own biases, prejudices or social norms, benefiting certain groups and harming others. Such biases could be present at all stages of development of these technologies.[5] The problem of biases can also be linked to the issue of structural inequality in general. Indeed, inequality gaps are likely to be exacerbated if neurotechnologies that pursue therapeutic or inclusionary purposes are disproportionately accessible to certain groups, especially at the early stage of their development and distribution.[6] Finally, the possibility of the use of neurotechnologies for human enhancement, i.e., to alter bodily or cognitive functions beyond what is necessary to maintain or restore good health[7] or beyond the existing human range, [8] could deepen existing inequalities and disparities, especially if they are available only to those who can afford them.

8. From a human rights perspective, what opportunities could the use of neurotechnologies bring? Can these opportunities be balanced against the identified risks and impact?

Both readout neurotechnologies (those that are limited to recording and decoding brain activity) and modification neurotechnologies (those that can change brain activity through stimuli) were developed, in general, for therapeutic purposes. Electroencephalograms, a reading technology, have been indispensable to the practice of medicine for decades. Several modifying neurotechnologies, especially prostheses and

[4] For a discussion of the relationship between neurotechnologies and the right to health in the United Nations system, see Jared Genser, Stephanie Herrmann, and Rafael Yuste, "International Human Rights Protection Gaps in the Age of Neurotechnology," *NeuroRights Foundation* (2022), p. 35–37; 40–42. Available online at: https://neurorightsfoundation.org/s/Neurorights-Foundation-PUBLIC-Analysis-5622.pdf.
[5] Goering et al., "Recommendations for Responsible Development and Application of Neurotechnologies," op. cit.
[6] Ídem.
[7] Ídem.
[8] CIB, *Report of the International Bioethics Committee of UNESCO (IBC) on the ethical issues of neurotechnology*, op. cit., par. 13.

invasive devices, are in the early stages of scientific development. The most commonly cited example of modification neurotechnologies are deep brain stimulators that produce electrical impulses to decrease or eliminate the tremors of advanced Parkison's disease. The use of these neurotechnologies for therapeutic purposes is increasing, and their mass use in clinical settings could be achieved sooner than previously thought. By way of example, as of 2019, more than 160,000 patients had received deep brain stimulation for the treatment of Parkinson's disease, and that number was estimated to grow by more than 12,000 new patients per year globally.[9]

Therefore, neurotechnologies have the potential to become an indispensable tool for medicine. Not only do they offer the possibility of making precise diagnoses and clarifying the pathological processes of certain diseases, but they could also be used for the prevention and treatment of countless neurological disorders which, in turn, can be the source of physical and/or mental disabilities. As an example, in the United States, deep brain stimulators have already been licensed for the treatment of Parkinson's disease, dystonia, epilepsy, obsessive-compulsive disorder, and seizures in the case of difficult-to-treat epilepsies.[10] Studies suggest that this technology could also treat severe depression, traumatic brain injury, stroke recovery, addiction, chronic pain, dementia, Tourette's syndrome, Huntington's disease and multiple sclerosis.[11]

Similarly, these technologies can become key tools to ensure accessibility for people with disabilities and, in turn, guarantee their right to independent living and inclusion in the community.[12] In particular, brain-computer interfaces already function as communication and control technologies for people with physical and/or intellectual disabilities by facilitating, for example, the expression of will, the operation of neuroprostheses, or the control of computers.[13] Certain modification neurotechnologies, such as cochlear implants, can also function as reasonable accommodations to ensure accessibility of information and communications for people with sensory or intellectual impairments. Again, for these technologies to be

[9] Darrin J. Lee et al., "Current and Future Directions of Deep Brain Stimulation for Neurological and Psychiatric Disorders: JNSPG 75th Anniversary Invited Review Article," *Journal of Neurosurgery JNS* 131, no. 2 (2019): 333–42.
[10] Mayo Clinic, op. cit.
[11] CIB, *Report of the International Bioethics Committee of UNESCO (IBC) on the ethical issues of neurotechnology*, op. cit., par. 21.
[12] Articles 9 and 19, UN Convention on the Rights of Persons with Disabilities (CDPD).
[13] Jonathan R Wolpaw et al., "Brain–Computer Interfaces for Communication and Control," *Clinical Neurophysiology* 113, no. 6 (2002): 767–91.

truly conducive to universal accessibility, it will be necessary to ensure equitable distribution and access to these technologies.[14]

Regarding whether these opportunities can be balanced against the identified risks, see answer to question 14 below.

International framework

14. What are the main international regulatory and governance gaps that you have identified as regards neurotechnology and human rights?

From an international human rights law perspective, balancing the opportunities created by these technologies against the risks already identified and their impact on human rights would require an international legal framework that can provide the kind of legal protection that the neurotechnological era requires. Under the "protection gap" theory, Yuste, Genser and Hermman argue that the IHRL is not equipped to address the human rights challenges posed by neurotechnology, nor to ensure the protection of individuals through the justiciability of legal rights such as identity, agency and mental privacy.[15]

These authors point out that, although the universal human rights system could partially cover some of these challenges, it is incomplete and imprecise, and cannot respond to the rapid development of these technologies.[16] Although the authors ascribe some value to interpretative developments or soft law instruments, they suggest that the optimum of protection would be achieved with the adoption of a new international treaty that incorporates "neuro-rights" expressly and that, eventually, has a specific supervisory body for the interpretation and development of its content.[17]

While we agree with the importance and convenience of having a specific legal framework in international human rights law, as it will be addressed in the answer to the next question, this does not mean that current

[14] Sara Goering and Eran Klein, "Neurotechnologies and Justice by, with, and for Disabled People," in *The Oxford Handbook of Philosophy and Disability*, Cureton y Wasserman eds. (Oxford University Press, 2020).
[15] Genser, Herrmann, and Yuste, "International Human Rights Protection Gaps in the Age of Neurotechnology," op. cit., p. 3.
[16] Rafael Yuste, Jared Genser, and Stephanie Herrmann, "It's Time for Neuro-Rights," *Horizons: Journal of International Relations and Sustainable Development*, no. 18 (2021), p. 160.
[17] Yuste, Genser, and Herrmann, "It's Time for Neuro-Rights," op. cit., p. 162.

treaties cannot be interpreted in a way that allows to address the risks of the use of these technologies and their impact on the enjoyment of human rights.

15. What actions would you advocate for to address these gaps and potential human rights impact at the international level? Please elaborate on specific normative or institutional measures you would propose and assess the feasibility of their implementation.

Without prejudice to the advantages of having a new international treaty that expressly incorporates "neuro-rights", existing human rights treaties can be interpreted in a way that responds to this issue. In the case of the inter-American system, several provisions of the American Convention on Human Rights and its interpretations given by the Inter-American Court of Human Rights can provide no lesser protection to human rights violations caused by neurotechnologies.

For example, the right to identity in the inter-American human rights system has a content similar to that suggested by those who advocate for "neuro-rights", in that it is defined as "the set of attributes and characteristics that allow the individualization of the person in society".[18] For the Inter-American Court, identity is something that is constantly being constructed on the basis of historical and biological experiences and that "can be affected by a number of situations or contexts"[19] - which could include the impact of technologies that act on the nervous system. The right to identity already protects the control over "the concept of oneself",[20] insofar as it guarantees (i) the free and autonomous construction of the personality, in accordance with legitimate individual convictions, (ii) the freedom to externalize that personality, and (iii) the right to have that externalization respected, with no other limitations than those imposed by the rights of others.[21]

[18] I/A Court H.R., Case Gelman v. Uruguay. Merits and Reparations. Judgment of February 24, 2011 Series C No. 221., par. 122; I/A Court H.R., Gender identity, and equality and non-discrimination with regard to same-sex couples. State obligations in relation to change of name, gender identity, and rights deriving from a relationship between same-sex couples (interpretation and scope of Articles 1(1), 3, 7, 11(2), 13, 17, 18 and 24, in relation to Article 1, of the American Convention on Human Rights). Advisory Opinion OC-24/17 of November 24, 2017. Series A No. 24.
[19] I/A Court H.R., Case Gelman v. Uruguay. Merits and Reparations. Judgment of February 24, 2011 Series C No. 221., par. 113.
[20] Goering et al., "Recommendations for Responsible Development and Application of Neurotechnologies," op. cit.
[21] I/A Court H.R., Advisory Opinion OC-24/17. Gender identity, and equality and non-discrimination with regard to same-sex couples. Series A No. 24, pars. 91-94.

The inter-American legal framework also dialogues with the idea of a "neuro-right" to agency or free will, granting protection similar to that proposed by Genser, Herrmann and Yuste. Human agency can already be considered protected under the unnamed right to identity which, according to the Inter-American Court, protects each individual "as a being who is self-determining and self-governing, that is, who is master of himself and of his acts".[22] Furthermore, the notion of agency also falls under Article 7(1) of the American Convention on Human Rights, which recognizes a right to personal liberty. The Court has held that this Article includes a "broad concept of liberty", which includes (i) a right to individual freedom of action, or the ability to do and not to do everything that is lawfully permitted and (ii) a right to self-determination, which prohibits any act that seeks to instrumentalize the person.[23]

As interpreted by the Inter-American Court of Human Rights, these rights not only protect control over one's own actions (agency), but also prohibit any action by the State - or by a private actor that can be attributed to the State - that turns a person "into a means to ends other than choices about his own life, his body and the full development of his personality"[24] (identity).

Therefore, different provisions of the American Convention could be used to address the challenges related to the use of modification neurotechnologies. Without prejudice to the development of more specific norms or new interpretations, the current content of the right to identity in the inter-American human rights system should be understood as prohibiting any form of non-consensual manipulation of the nervous system that may affect the free construction of the personality. This would include, for example, the deliberate alteration of speech, ways of thinking, political opinions, or the introduction of artificial memories. All of these issues can be considered undue interference with the "historical and biological experiences" that lie at the heart of the right to identity. For its part, the right to self-determination also preserves our capacity to act, or to be masters of our actions, and categorically prohibits any arbitrary interference in the development of those thoughts or actions.

[22] Ídem, par. 89.
[23] Ídem, par. 88 (citing Case I.V. vs. Bolivia); I/A Court H.R., Case of Artavia Murillo et al. (In Vitro Fertilization) v. Costa Rica. Preliminary Objections, Merits, Reparations and Costs. Judgment of November 28, 2012. Series C No. 257. par. 142 (citing Case Chaparro Álvarez and Lapo Íñiguez vs. Ecuador).
[24] I/A Court H.R., Advisory Opinion OC-24/17. Gender identity, and equality and non-discrimination with regard to same-sex couples. Series A No. 24, par. 88 (citing Case I.V. vs. Bolivia).

Thus, the use of technologies to "influence a person's behavior, thoughts, emotions or memories"[25] without his or her consent through brain stimulation can be considered a form of personality manipulation prohibited by the American Convention. This is independent of the fact that the Inter-American Court of Human Rights has not expressly addressed the use of technology as a form of coercion, because its framework has been broad enough to include any act or omission that causes a person to lose control over himself/herself and his/her actions, or that turns him/her into a means for someone else's ends.

16. What international organization, bodies, or agencies would be in your opinion best placed to oversee and prevent potential abuses or misuses resulting from the use of neurotechnologies?

The inter-American human rights system has various mechanisms for the protection of human rights that would allow the development of standards applicable to the new challenges posed by the use of neurotechnologies. The strategic use of these mechanisms has allowed human rights standards to be created with respect to novel issues. This, for example, through the monitoring of the human rights situation by the Inter-American Commission on Human Rights (IACHR) through thematic reports and public hearings. Indeed, at its 184th period of sessions, the IACHR held, on June 21, 2022, the first public hearing on human rights and neurotechnologies.[26]

On the other hand, the petition and case system of the IACHR and the Inter-American Court can be an effective mechanism for the development of inter-American standards applicable to emerging issues. For example, the Inter-American Court, making use of the evolutionary interpretation of inter-American instruments, can establish new international obligations with respect to emerging issues and order States to adopt laws, regulations and public policies to address situations of lack of protection of human rights in the face of new realities.

This strategic use of inter-American human rights protection mechanisms could also be replicated in other regional systems and in the universal system.

Also, within the framework of the Organization of American States (OAS), there is the possibility of adopting inter-American norms through other bodies, such as the OAS General Assembly and the Inter-

[25] Yuste, Genser, and Herrmann, "It's Time for Neuro-Rights," op. cit., par. 160.
[26] IACHR, 184 period of sessions, Human Rights and neurotechnologies, June 21, 2022.

American Juridical Committee (as will be indicated below). Through the adoption of soft law instruments or binding treaties, the OAS is the natural forum in the American hemisphere to guide States in the creation of new legal frameworks on emerging issues.

24. Please outline the relevant work that your organization, agency or department has done in relation to neurotechnology and human rights. Please share the main outcomes and recommendations (if applicable).

The Health and Human Rights Initiative has conducted preliminary research on the challenges posed by neurotechnologies to the enjoyment of human rights. This initial research seeks to offer a first proposal for framing this emerging issue under the inter-American human rights system, particularly under the American Convention on Human Rights. The research analyzes how the current inter-American legal framework can protect against the use and abuse of neurotechnologies, beyond the need and convenience of developing a legal framework that deals specifically with neuro rights.

Silvia Serrano Guzmán, who co-directs the O'Neill Institute's Health and Human Rights Initiative and Ríos-Rivers, is a member of the expert group on neuro-rights that drafted the declaration on "Neuroscience, Neurotechnologies and Human Rights: New Legal Challenges for the Americas" adopted by the Inter-American Juridical Committee (CJI) of the Organization of American States (OAS) on August 11, 2021. The CJI is the OAS's advisory body on legal matters, responsible for promoting the progressive development and codification of international law and for studying the possibility of standardizing the laws of the countries of the Americas. This declaration inaugurates a renewed debate on the relationship between science, technology and human rights in the Americas, and a precedent for future and necessary debates that must take place within the framework of the United Nations and the OAS[27].

Silvia Serrano Guzmán also participated at the first hearing before the IACHR about neurotechnologies and human rights together with Neuro Rights Initiative (Columbia University), Kamanau Foundation, the Pro Bono Network of the Americas, the Inter-American Human Rights Institute and Ronda Foundation[28].

[27] Rafael Yuste and Ciro Colombara. Univisión Noticias. Latinoamérica se pone a la vanguardia en la protección de la privacidad mental. August 13, 2021.
[28] IACHR, 184 period of sessions, Human Rights and neurotechnologies, June 21, 2022.

26. What are the main international regulatory and governance gaps that you have identified as regards neurotechnology and human rights?

As indicated in the response to question 14, Yuste, Genser and Hermman argue that international human rights law is not prepared to address the human rights challenges posed by neurotechnology.[29] This is because the proliferation of these technologies puts at risk some rights that are not expressly recognized in existing treaties or that cannot provide the legal protection that the neurotechnological era requires. Optimal protection would therefore be achieved with the adoption of a new international treaty that expressly incorporates "neuro-rights".[30]

The existing literature has summarized these dangers into five specific concerns, which can be considered the focus of this international regulatory gap:[31]

- *Identity:* this refers to the possibility that adverse or unintended effects of neurotechnologies may compromise the user's sense of identity in at least two ways. First, by modifying certain relatively stable personality characteristics, such as modulation or manner of speech, political orientation, or behavior. By way of example, side effects associated with deep brain stimulation can include psychosis, hypersexuality, pathological gambling, and mood swings[32] - all issues that have a direct impact on the user's personality. Second, modification neurotechnologies have the potential to influence memory formation, a fundamental component of identity or personal narrative. Through the production of optical stimuli, brain stimulators could introduce artificial memories into the brain, or alter existing ones, generating false memories in the user. Although underdeveloped, the possibility of modifying memory has already been verified in animals. [33]

- *Agency:* it refers to the danger of loss of control over one's own thoughts and actions. It is suggested that, by allowing the control of external objects without physical effort, reading neurotechnologies could blur individual boundaries (i.e., where the human body begins and ends), which threatens

[29] Genser, Herrmann, and Yuste, "International Human Rights Protection Gaps in the Age of Neurotechnology," op. cit., p. 3.
[30] Yuste, Genser, and Herrmann, "It's Time for Neuro-Rights," op. cit., p. 162.
[31] Goering et al., "Recommendations for Responsible Development and Application of Neurotechnologies," op. cit.
[32] CIB, *Report of the International Bioethics Committee of UNESCO (IBC) on the ethical issues of neurotechnology*, op. cit., par. 22; Mayo Clinic, op. cit.
[33] Goering et al., "Recommendations for Responsible Development and Application of Neurotechnologies," op. cit.

traditional notions of agency. At the same time, the possibility that brain stimulators can be remotely regulated by third parties, rather than by the user or patient, also threatens mastery over one's own actions. Finally, the combination of modifying technologies with machine learning or artificial intelligence raises that risk of loss of physical and mental self-determination almost to the extreme, opening the door to a complete dissociation between the user's wishes and his or her actions. The most commonly cited example is that of a person under brain stimulation to treat depression who claimed to be unsure whether his actions were due to his free will, his depression, or the brain stimulator.[34]

- *Privacy:* it refers to the fact that the brain contains an extraordinary amount of personal information - "neural data" or "brain data" - that should be considered highly sensitive and closely linked to a person's identity. This is data that reflects an individual's neural activity and therefore contains unique information about his or her physiology, health and mental states.[35] Neurotechnologies have the ability to access all of this information, including subconscious tendencies, biases and other information beyond a person's control, and can even store it for extended periods of time. Although individuals may have an interest in the disclosure of such information (e.g., someone who undergoes an EEG to find out if they have a schizoaffective disorder), the possibility of commercial development of neurotechnologies for mass consumption poses the certain risk of unauthorized disclosure or use of neural data.

- *Biases:* refers to the possibility of algorithmic biases. Because neurotechnologies are developed by humans, there is a risk that they may reflect their own biases, prejudices or social norms, benefiting certain groups and disadvantaging others. Such biases could be present at all stages of development of these technologies.[36] The problem of biases can also be linked to the issue of structural inequality in general. Indeed, inequality gaps are likely to be exacerbated if neurotechnologies that pursue therapeutic or inclusionary purposes are disproportionately accessible to certain groups, especially at the early stage of their development and distribution.[37]

[34] Rafael Yuste et al., "Four Ethical Priorities for Neurotechnologies and AI," *Nature* 551, no. 7679 (2017): 162; Goering et al., "Recommendations for Responsible Development and Application of Neurotechnologies," op. cit.
[35] OCDE, *Recommendation of the Council on Responsible Innovation in Neurotechnology*, op. cit., párr. II.
[36] Goering et al., "Recommendations for Responsible Development and Application of Neurotechnologies," op. cit.
[37] Ídem.

- *Human enhancement*: this refers to the possibility that modifying neurotechnologies may be used to alter bodily or cognitive functions "beyond what is necessary to maintain or restore good health"[38] or "beyond the existing human range".[39] Notwithstanding the ethical dilemmas, those who focus on the human enhancement implications for human rights warn about (i) the risk of social pressure to submit to the use of these technologies, and (ii) their impact on deepening already existing inequalities and disparities, especially if they are available only to those who can afford them. In that sense, this is a concern similar to the dangers of agency and bias.

To ensure the justiciability of "neuro-rights", it is important that, in addition to the existence of specific treaties, these have a supervisory body for the interpretation and development of their content.

Finally, the "neuro-rights" movement has warned that the threat to these legal rights could be accidental, i.e., be an adverse or unintended effect of these devices. Therefore, thinking about the risks of neurotechnologies requires taking into account all the effects associated with their use: explicit intentional ones (e.g., the deliberate use of reading technologies to alter memory), intentional ones concealed under the positive veil of neurotechnologies (such as unrestricted access to neural data as a consequence of the use of reading neurotechnologies), and/or accidental or unintended effects. To address all these risks, it is essential that the substantive content of the rights mentioned so far be complemented by additional safeguards, i.e., by other state obligations that are enforceable throughout the process of development and implementation of these technologies.

These safeguards include: (i) the creation and implementation of specific regulatory frameworks with supervision and oversight mechanisms; (ii) the duty to obtain prior free and informed consent; (iii) the guarantee of access to information; and (iv) access to effective remedies.

While these safeguards are already present in regional systems such as the inter-American human rights system, a specific treaty and its corresponding monitoring mechanism should include such safeguards.

[38] Ídem.
[39] CIB, *Report of the International Bioethics Committee of UNESCO (IBC) on the ethical issues of neurotechnology*, op. cit., par. 13,

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