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PROGRESS REPORT: DRAFT INTER-AMERICAN PRINCIPLES ON NEUROSCIENCES, NEUROTECHNOLOGIES AND HUMAN RIGHTS

(Presented by Dr. Ramiro Orias Arredondo)

Preamble

CONSIDERING that advances in neuroscience and the development of neurotechnologies have made it possible to tap into individuals' brain activity, which forms the essence of their personality, and thus raises major ethical and legal challenges in the human rights arena. As such, inter-American-level principles are needed for effective, systematic, and transparent integration of the use of neurotechnologies. The aim is to safeguard fundamental human rights such as dignity, equality, and non-discrimination, free development of personality, identity and autonomy, the right to privacy and confidentiality, physical, psychological, and neurocognitive well-being, physical and mental health, and access to justice, among other things;

REAFFIRMING that the Universal Declaration of Human Rights recognizes the right to the free development of personality, enshrining equality and human freedom; the enjoyment of economic, social and cultural rights; and education as a means for the development of the human personality;

MINDFUL that the Charter of the Organization of American States (OAS) declares that scientific and technological development should strengthen the fundamental rights of individuals, while seeking the overall betterment of the individual and as a foundation for democracy, social justice, and progress; and that the Social Charter of the Americas adopted by the OAS establishes that scientific and technological development should help to improve living standards and achieve integral development for people, therefore it is necessary to take steps to ensure that the application of innovations benefits everyone;

RECALLING that according to the American Declaration of the Rights and Duties of Man, all persons are born free and equal, in dignity and rights and, being endowed by nature with reason and conscience, should conduct themselves in a spirit of fraternity one to another. Fulfillment of duty by each individual is a prerequisite to the rights of all. Likewise, and pursuant to the American Convention on Human Rights (Pact of San José), the states must respect the rights and freedoms recognized therein and ensure to all persons the free and full exercise of thereof, undertaking to adopt specific measures to achieve progressive development and give full effect to the rights derived from the economic, social, educational, scientific, and cultural standards set forth in the Charter of the Organization of American States (OAS);

THAT, furthermore, the Additional Protocol to the American Convention on Economic, Social and Cultural Rights (Protocol of San Salvador) recognizes the right of every person to enjoy the benefits of scientific and technological progress;

NOTING that the Inter-American Juridical Committee had approved the Updated Principles on Privacy and Personal Data Protection, CJI/doc.638/21, in April 2021;

HIGHLIGHTING the adoption of the United Nations Educational, Scientific and Cultural Organization (UNESCO) International Bioethics Committee's report on "Ethical issues of neurotechnology," published in December 2021;

RECALLING recent international initiatives on the ethical, social, and human rights challenges posed by neuroscience and neurotechnologies, such as the "Recommendation on Responsible Innovation in Neurotechnology," adopted in December 2019 by the Organization for Economic Cooperation and Development (OECD); the Report of the Council of Europe on "Common Human Rights Challenges Raised by Different Applications of Neurotechnologies in the Biomedical Field," adopted in October 2021; as well as, recent domestic initiatives in Chile and Brazil on legislation in this area; and

BEARING IN MIND that the Inter-American Juridical Committee adopted the Declaration on Neuroscience, Neurotechnologies and Human Rights: New Legal Challenges for the Americas, CJI/DEC. 01 (XCIX-O/21), in August 2021; the text of said Declaration, as well as the text of this Report, has benefited from substantive input and specialized recommendations from an interdisciplinary Committee of Experts comprising scientists and jurists, specialists covering a variety of issues that come together in the principles addressed herein.¹

The Inter-American Juridical Committee of the Organization of American States (OAS) hereby adopts the following document as:

Progress Report on:

"Inter-American Principles on Neurosciences, Neurotechnologies and Human Rights"

1. Identity and autonomy

Neurotechnologies must never interfere with identity, free will, nor the free development of the personality. It is vitally important to safeguard and guarantee each person's control over his or her own individual identity. Ensure neurocognitive self-determination, sovereignty, and freedom in decision-making.

2. Human rights protection by design

States must ensure that human rights are effectively, systematically, and transparently incorporated and respected from the start of design of neurotechnologies, in implementing and evaluating the latter. A subject's neurocognitive substrate is the product of the individual's brain activity and is therefore the essence of his or her personality, and ensuring that human rights are protected in this area is essential.

3. Sensitive personal data. Neuroprivacy

Part of privacy, among other things, neural activity is therefore protected by privacy-related human rights standards. Neural data derived from such activity are sensitive personal data that are especially susceptible to inflict considerable harm on individuals if misused.

Data officers should adopt enhanced privacy and security measures that are commensurate with the data sensitivity and capacity to harm data subjects. Limits should be enforced on the application of decryption techniques that can identify or make an individual identifiable, especially with datasets that are shared with third parties.

4. Neural Data Security and Control

The guarantee of freedom to decide on access to neural activity and its potential handling extends to the security of the neural data collected and the full control and disposal of such data. Anyone responsible for the handling of neural data must adopt enhanced neural data security measures,

1. The Committee of Experts comprises: Eduardo Berton, Ciro Colombara, Francesca Fanucci, Verónica Hinestroza, Amelie Kim Cheang, Tomás Quadra Salcedo, Moisés Sánchez, Silvia Serrano Guzmán y Rafael Yuste.

and must furthermore establish and keep clear management plans and protection guidelines for the collection, storage, organization and access of the data, regardless of the kind of handling they do, in order to ensure strict safeguards over the security of the data.

5. Informed consent

The free, informed, specific, unequivocal, and condition-free consent from those who allow access to, or handling of, neural activity must be ensured, and appropriate legal, administrative, physical, and technical measures taken to guarantee confidentiality, integrity, and availability of the personal data. Consent being a prerequisite for access to a collection of brain information, the handling of such information must be strictly limited to the terms of the consent. Anyone granting consent must also be able to revoke same, and must be able at any time to request the deletion of stored neural data processed, to which end the data controller must establish mechanisms that are simple, agile, effective, and cost-free. This consent must pay close attention when the information processed is intended to be used to develop predictive models to draw conclusions about behavior. In seeking the consent of children and adolescents, the principle of progressive autonomy must be taken into account, along with the provisions of the rules of representation provided for under the domestic law of the states.

6. Confidentiality and guaranteeing non-intrusion

States have a duty to ensure denial of intrusion and access to brain information without the express consent of the individual and with all the safeguards in place for protecting personal data. Everyone has a right to the privacy and integrity of his or her brain data and not to suffer alterations, manipulations and/or modifications of brain information that may jeopardize or affect his or her freedom of thought, autonomy, dignity, health, and personal safety.

7. Equality and nondiscrimination [neurodiscrimination]

Neurotechnology advances and uses must never cause inequalities to be maintained or increased or discriminations to be exacerbated, especially against the most vulnerable groups. To this end, the development of neurotechnologies must be transparent and accessible to all people and must be part of responsible innovation policies that will redound to the benefit of equity of society as a whole, especially in terms of improving the health conditions of the population.

8. Equal access to neurotechnologies

Equitable access to the use and benefits of neurotechnologies must be guaranteed, by removing barriers to entry and by helping to ensure that everyone can fully enjoy the rights to health and education. States should encourage public policies, as well as international cooperation mechanisms, that are designed to promote education and access to healthcare products and services for all people, in order to ensure that they can benefit from advances in neuroscience and neurotechnology. Likewise, states must ensure there is a balance between individual and collective interests in the development, access, use, and marketing of neurotechnologies within the framework of law and international standards on “Business and Human Rights,” in keeping with their obligations to respect and guarantee the rights in question.

9. Transparency and proactive accountability

States have an obligation to ensure that all state or non-state actors involved in handling and developing neurotechnology data must ensure transparency and access to information on how these technologies are researched, developed, applied, and operated, and the impact they have on human rights, as well as accountability regarding the handling of neural data in their possession. Transparency calls for sufficient information to be published proactively or documented as regards how the technology is designed and how it ought to be used. After a technology is approved for use, the foregoing information should still be published and documented on a regular basis and in a timely manner.

10. Data Governance

Neural data handlers must put the information they collect to appropriate use, and are required to provide readily understandable information about the use of the data. Public authorities should establish safeguards on how the data are governed, protected, and disposed of; and should regularly publish information on how decisions have been made regarding the adoption of these technologies and how they will be periodically evaluated, their uses, and their known limitations, which can facilitate external auditing and oversight. States should establish independent oversight bodies that are open to participation from the relevant parties, with autonomous management, to monitor and promote the protection of neural data in accordance with these Principles.

11. Control of the increased of cognitive enhancement

The use of neurotechnologies to enhance or augment the cognitive abilities of individuals should be subject to enhanced control, limits, and human rights safeguards. Cognitive enhancement encompasses the use of technologies to enhance human cognitive abilities, ranging from traditional mechanisms such as education to the more disruptive means such as brain stimulation. States should regulate the underlying assumptions and terms of use of neurotechnologies, which are intended, beyond their therapeutic or health application, to increase or enhance cognitive abilities. States should establish mechanisms to prevent and hinder the emergence of a possible social and educational gap between people who have decided to enhance their skills and those who have chosen or are unable to do so. Domestic laws should more specifically define the normative and regulatory context of neuroenhancement to ensure that human dignity is effectively safeguarded and protected.

12. Development of neurosciences and neurotechnologies

States must ensure that the pursuit of neurosciences and neurotechnologies will serve to benefit everyone while contributing to the enjoyment of economic, social, and cultural rights. States should commit themselves to adopting measures, especially economic and technical measures, to gradually achieve full enjoyment of the rights flowing from economic, social, health, education, scientific, and cultural standards.

13. Neurocognitive integrity, safeguards, and moratoriums

Mechanisms should be created to prevent neurotechnologies from being used for malicious purposes that might result in neurotechnological interventions intended to damage or affect brain activity or impact the exercise of human rights, or for other illegitimate purposes. States should establish mechanisms to prohibit the development, use and marketing of malicious neurotechnologies and should set parameters to limit those neurotechnologies that are prohibited based on the risk they pose to human rights.

14. Supervision and oversight

The role of states is to enact rules to ensure that the use and application of these technologies do not adversely affect the rights of individuals, so as to safeguard the interests and freedoms of the subjects of neural data and to protect the right to health and education. The absence of specific regulations on neurotechnologies, as well as their scope and impact, poses a risk that those who create these technologies and/or control large artificial intelligence (AI) systems that decode neural information could illegitimately manipulate their neurocognitive substrate of emotions, feelings, and decisions.

15. Access to effective protection of the neurocognitive substrate

States must ensure mechanisms are in place for the effective protection of neurocognitive substrate and ensure access to remedies in administrative and judicial proceedings alike, guaranteeing due process, to monitor and promote the protection of human rights in accordance with these Principles.

This Progress Report is adopted for the purpose of continuing efforts to build consensus towards drafting the **Inter-American Principles on Neurosciences, Neurotechnologies and Human Rights**, against the backdrop of both a complex new era in terms of the scope and speed of the events taking place and the need to guarantee observance of and respect for human rights.