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

Background

In accordance with Human Rights Council <u>resolution 51/3</u>, the Advisory Committee is preparing a study "on the impact, opportunities and challenges of neurotechnology with regard to the promotion and protection of all human rights" to be presented to the Council at its fifty-seventh session (September 2024). In the preparation of this study, the Advisory Committee was asked "to seek the views and inputs from, and to take into account the relevant work already done by, stakeholders, including Member States, international and regional organizations, the Office of the United Nations High Commissioner for Human Rights, the special procedures of the Human Rights Council, the treaty bodies, other relevant United Nations agencies, funds and programmes within their respective mandates, national human rights institutions, civil society, the private sector, medical and technical communities, academic institutions and other relevant stakeholders".

Neurotechnologies are defined for the purposes of this study, as those devices and procedures used to access, monitor, investigate, assess, manipulate and/or emulate the structure and function of the neural systems of natural persons.¹ They are meant to either record signals from the brain and "translate" them into technical control commands, or to manipulate brain activity by applying electrical or optical stimuli.²

Deadline

Responses to the questionnaire can be submitted until **2 July 2023**. Nonetheless, on exceptional basis, late responses or further information relevant to the work of the Advisory Committee on this topic may be accepted.

Questionnaire

Please answer the questions that are most relevant to your field of expertise or operation. There is no need to answer questions that may not be relevant to your work. Please respond as succinctly as possible and provide examples and substantive information where possible.

¹ OECD, "Recommendation of the Council on OECD Legal Instruments Responsible Innovation in Neurotechnology", 2019; "Neurotechnology and Society: Strengthening Responsible Innovation in Brain Science", OECD Policy Papers, November 2017, p. 49.

² UNESCO, "Report of the International Bioethics Committee of UNESCO (IBC) on the Ethical Issues of Neurotechnology", 2021, p.5.

QUESTIONS

I. All stakeholders (core questions)

General

1. Has your country taken any policy action or initiative in relation to neurotechnology and human rights at the national level? If so, please share any relevant information.

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- **2.** Is there any actor in the public or private sector developing this kind of technology in your country? Please provide information, if possible.
- **3.** Indicate your level of awareness (high/medium/low) in relation to the state of development of neurotechnologies and preparedness to tackle the challenges posed by the early commercialization of these technologies.

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? Will such risks be amplified by the development of consumer-oriented neurotechnologies?
- 6. What groups are more vulnerable or at risk? Please, identify three and explain why.
- 7. What methods can be used to identify and assess the potential risks and impact of these technologies on human rights, in particular the human rights of persons with disabilities and other groups in vulnerable situations? Will such risks be amplified by the development of consumer-oriented neurotechnologies?
- **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?

National framework

- **9.** Is the national legal framework adequate to face the challenges that the development, test and use of neurotechnologies pose to human rights? Please explain briefly and indicate the relevant pieces of legislation and whether there are plans to develop any (or further) legislation.
- **10.** Does national legislation on privacy and data protection cover mental privacy³ and/or personal brain data?⁴ Please explain.

³ "Mental privacy" refers to the explicit protection of individuals against the unconsented intrusion by third parties into their mental information (be it inferred from their neural data or from proxi data indicative of neurological, cognitive and/or affective information) as well as against the unauthorized collection of those data. Ienca, M. and Andorno, R. "Towards new human rights in the age of neuroscience and neurotechnology", *Life Sciences, Society and Policy*, Vol. 13, n. 5, 2017.

⁴ "Personal brain data" or "neural data" is defined as the data relating to the functioning or structure of the human brain of an identified or identifiable individual that includes unique information about their psicology, health or mental states (OECD, 2019).

- **11.** From a human rights-protection perspective, what are the main domestic regulatory gaps that can be identified? What legal (or other) measures are necessary to avoid human rights violations arising from the use of neurotechnologies in your opinion?
- **12.** Is your national institutional framework for human rights well-equipped to address the new challenges posed by neurotechnologies?
- **13.** What national entity would be best placed to exercise scrutiny and oversight to prevent potential abuses or misuses derived from the use of neurotechnologies? Is there any procedure in place to that effect?

International framework

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

II. Private actors and other stakeholders with experience or expertise in the subjectmatter, such as medical and technical communities, and academic institutions (specific questions)

- 17. What specific characteristics would you emphasise as unique and distinctive of neurotechnologies?
- **18.** Have you introduced or are you considering introducing any adjustment to your activities or business model such as incentives, indicators or performance metrics of governance in response to these specific characteristics? Please explain.
- **19.** Has your company/organization undertaken any specific action or measure to mitigate impacts arising from the use of neurotechnologies? Are any of these actions or measures specifically addressed to mitigate human rights risks?
- **20.** Does your company or organization implement the principles for responsible innovation in neurotechnology?⁵ Please elaborate.
- **21.** Has your company or organization developed or plans developing (or adopting) an ethical code of conduct or human rights strategy for the development, testing or commercialization of neurotechnologies? Please outline such initiatives and provide a copy of relevant documents, if possible.
- **22.** What national regulation or framework do you consider is needed to avoid a potentially negative human rights impact of neurotechnology?

⁵ See, for example: OECD, "Recommendation of the Council on OECD Legal Instruments Responsible Innovation in Neurotechnology", 2019.

23. Which regulatory framework such as application of specific, sectorial, national, autoregulation or a combination of them do you believe is best suited to the specific characteristics of neurotechnologies?

III. International and regional organizations; United Nations agencies, funds and programmes; national human rights institutions; and civil society (specific questions)

- **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).
- **25.** Please describe any measures undertaken aimed at coordinating, collaborating or seeking synergies with the work of other organizations in relation to neurotechnology.
- **26.** What are the main international regulatory and governance gaps that you have identified as regards neurotechnology and human rights?

IV. Special Procedures of the Human Rights Council (specific questions)

- **27.** Has your mandate considered the issue of neurotechnology and human rights? If so, please indicate the main outcomes and recommendations and include relevant references and links.
- **28.** What impact of neurotechnology do you foresee in relation to the human rights within your mandate? What actions would you propose or undertake to mitigate any adverse impact or risk? Please highlight the risks attached to this issue and potential opportunities, if relevant.
- **29.** What actions could be undertaken by the Coordination Committee of Special Procedures to address any negative human rights impact arising from neurotechnology?
- **30.** What are the gaps, if any, in the existing international human rights protection framework to address the impact of neurotechnology? How could they be best addressed?
- **31.** How could the current international human rights framework be best used or developed to address the impact, opportunities and challenges of neurotechnology with regard to the promotion and protection of all human rights?

V. United Nations Treaty Bodies (specific questions)

- **32.** Has your treaty body considered directly or indirectly the issue of neurotechnology and human rights (while considering individual complaints, examining periodic reports or elaborating general comments)? If so, please indicate the main outcomes and recommendations (include relevant references and links).
- **33.** What impact of neurotechnology on human rights do you foresee from the perspective of your mandate? Please highlight the risks attached to this issue and potential opportunities, if relevant, and indicate what actions would you propose or undertake to mitigate risks.
- **34.** What are the gaps, if any, in the existing international human rights protection framework to address the impact of neurotechnology? How could they be best addressed?

35. How could the current international human rights framework be best used or developed to address the impact, opportunities and challenges of neurotechnology with regard to the promotion and protection of all human rights?

VI. Office of the United Nations High Commissioner for Human Rights (specific questions)

- **36.** What work is OHCHR currently carrying out in the field of neurotechnology and human rights? Please provide any relevant information such as links to reports, background material, sections or units involved, etc.
- **37.** What are the gaps, if any, in the existing international human rights protection framework to address the impact of neurotechnology? How could they be best addressed?
- **38.** How could the current international human rights framework be best used or developed to address the impact, opportunities and challenges of neurotechnology with regard to the promotion and protection of all human rights?