**Global consultation on the first draft of the Recommendation on the Ethics of Neurotechnology**

Deadline: 12 July 2024
Survey link: https://unesco-2023.limesurvey.net/984436?lang=en
** Open questions have 5000 character limit*

# Your personal information

**I am contributing to this consultation:**
*Choose one of the following answers*
- On my own behalf (as an individual)
- On behalf of an institution/company

**Age group**
*Choose one of the following answers*
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

**Gender**
*Choose one of the following answers*
- Male
- Female
- Other

**Nationality:** **Italian, French, American**

**Institutional affiliation**
*Select all that apply*
- ○ Permanent Delegation to UNESCO
- ○ National Commission to UNESCO
- ○ Governmental body
- ○ UN entity
- ○ International and Regional Organization (other than UN)
- ○ Civil Society
- ○ Industry/Private sector
- ○ Entrepreneur
- ○ Academia/ University
- ○ Non Governmental Organization (NGO)

- Media
- General public
- Other:

**Please specify your institutional affiliation (if applicable):** Dr. Claudia Roda and Dr. Susan Perry, The American University of Paris and UNESCO co-chairs in AI and human rights; Dr. Tara White, Brown University, School of Public Health, Carney Institute for Brain Science, and Watson Institute Center for Human Rights and Humanitarian Studies; Nicole Santiago, JD, lawyer specialised in human rights and emerging technologies.

**Area of work/research**
*Select all that apply*

- Healthcare
- Neurology, neurotechnology and related areas
- Psychology (clinical, cognitive, others)
- Engineering, Tech, AI
- Economics, Marketing
- Ethics, Philosophy
- Law, Human Rights
- Gender
- Youth
- Other:

# Definition and Scope

**1.a. The Draft Recommendation defines neurotechnology as "devices and procedures used to understand and/or influence, access, monitor, assess, emulate or modulate, the structure and function of the nervous systems of human beings and other animals" (para 2).**

**Do you agree with this definition?**

- Yes
- No
- No opinion

**1.b. If you replied "no" to the previous question, please suggest alternative wording.**
n/a

**2.a. Is there an important aspect of neurotechnology that the scope (see II.2) does not capture?**

- Yes
- No
- No opinion

**2.b. If you replied "yes" to the previous question, please explain:**
Throughout the document, it is unclear the definition of 'health', 'health-related', and 'medical' devices and applications. The meaning of these key terms is necessary to understand the scope and definitions provided in section II.1 and II.2, as well as the applicability of many recommendations in Section V.

**3.a. Do you think the scope is too broad?**
- ○ Yes
- ○ No
- ○ No opinion

**3.b. If you replied "yes" to the previous question, please explain why.**
n/a

**4.a. Do you think the way intersection of Artificial Intelligence (AI) and Neurotechnology is presented in the document encompasses well the speed and depth of developments in this field?**
- ○ Yes
- ○ No
- ○ No opinion

**4.b. If you replied "no" to the previous question, please suggest concrete wording:**
(1) Throughout the document, language should be amended to clarify that any list (e.g., risks, challenges, examples) is non-exhaustive and likely to evolve.
(2) Para. 28 should include risks related to poor data quality and incomplete data sets.

**5.a. Neural data is defined as "quantitative data about the structure, activity and function of the nervous system of a living organism. They encompass data relating to a nervous system's activity, including both direct measurements of neuronal structure, activity and/or function (e.g., neuronal firing or summed bioelectric signals from EEG) and indirect functional indicators (i.e., blood flow in fMRI and fNIRS). At the neurobiological level, neural data are the most direct correlates of mental states, as all cognitive and affective activity is primarily processed in the nervous system. Therefore, the prospect of decoding or modifying neural activity implies the possibility of decoding or modifying cognitive and affective processes" (para 7).**

**Do you agree with this definition?**
- ○ Yes
- ○ No
- ○ No opinion

**5.b. If you replied "no" to the previous question, please suggest alternative wording.**
(1) Neural data can also be qualitative.

(2) (2) The meaning of “the prospect of decoding or modifying neural activity implies the possibility of decoding or modifying cognitive and affective processes” is not clear.

# Approach

**6.a. Do you think that the ethical challenges (see III.3, pages 7-8) are adequately identified and described?**

- ○ Yes
- ○ No
- ○ No opinion

**6.b. If you replied "no" to the previous question, please explain:**

Throughout the document, language should be amended to clarify that any list of examples is non-exhaustive and likely to evolve (e.g., para. 26 ‘issues’ listed are not exhaustive, para. 27 ‘worrying prospects’ listed are not complete).

**7.a. This Recommendation adopts a human centered approach (see III.2). Is it adequately reflected in the draft document?**

- ○ Yes
- ○ No
- ○ No opinion

**7.b. If you replied "no" to the previous question, please explain:**

(1) ‘Human flourishing’ and ‘human-centered approach’ should be defined.
(2) In para. 20, neurotechnologies also raise significant human rights challenges.
(3) In para. 21, neurotechnologies also impact physical states.
(4) In para. 22, human rights are also deeply rooted in mental functions. See work by co-author Dr. Tara White on neural bases of universal human rights to agency, freedom from want, freedom from fear, uniqueness, and unconditionality. White, T., Gonsalves, M. (2021) Dignity neuroscience. Annals of New York Academy of Sciences. Vol. 1505, Issue 1.

# Values and principles

**8.a. Would you endorse the values identified in the document (pages 8-12)?**

- ○ Yes
- ○ No

○ No opinion

**8.b. If you replied "no" to the previous question, please explain:**
While we agree with the values and principles listed, the organisation of Section IV is not clear. Many of the ideas presented in the IV.1 'Values' section also relate to fundamental rights, and there is not a clear division between principles and rights in Section IV.2. We would recommend a restructuring of Section IV.

**9.a. Is there a value that is missing?**
○ Yes
○ No
○ No opinion

**9.b. If you replied "yes" to the previous question, please provide concrete language.**
n/a

**10.a. Would you endorse the principles identified in the document (p. 12-14)?**
○ Yes
○ No
○ No opinion

**10.b. If you replied "no" to the previous question, please explain:**
n/a

**11.a. Is there a principle that is missing?**
○ Yes
○ No
○ No opinion

**11.b. If you replied "yes" to the previous question, please provide concrete language.**
Add Principle of necessity: Like in data collection, neurotechnologies should only be developed and used in cases where neurotechnology is strictly needed to achieve a specific benefit and other means are insufficient to achieve the benefit. Add Right to consent: Any individual exposed to neurotechnologies must give full free, prior and informed consent; this should not be limited to the academic or medical use of neurotechnologies. This consent should be an explicit, active opt-in, meaning it cannot be bundled or hidden in a 'user agreement'. Additionally, consent should be specific to each instance of use or reuse of data (modeled after ethics guidelines for research with human participants) and should be specific and time-bound (e.g., allow use of data for 5 years or until end of research project, whichever comes first). Add Right to benefit from scientific progress and right to-opt out: ICESCR Art. 15 enshrines the right to benefit from scientific progress, including neurotechnologies. However, the right does not create an obligation on individuals to benefit from or use technologies. "[ICESCR] States parties must guarantee everyone the right to choose or refuse the treatment they want with the full

knowledge of the risks and benefits of the relevant treatment." (UN CESCR, General comment No. 25 (2020), E/C.12/GC/25).

**12.a. Do you think that the challenges raised by neurotechnology are adequately addressed by the human-rights framework?**

- ○ Yes
- ○ No
- ○ No opinion

**12.b. If you replied "no" to the previous question, please explain why and provide concrete suggestions if something is missing.**

n/a

# Areas of policy actions/recommendations

**13.a. Is the policy area section well structured?**

- ○ Yes
- ○ No
- ○ No opinion

**13.b. If you replied "no" to the previous question, please provide concrete suggestions.**

The sections should be reorganised to provide general policy recommendations first, then additional recommendations specific to vulnerable groups. As written, recommendations for specific groups do not clearly apply to all persons even though they should have wide applicability. For example, para. 99 on prohibiting the misuse of neurotechnologies should apply to all persons, not only children. Additionally, some recommendations are presented in specific context, but should be more widely used. For example, para. 156 on privacy impact assessments is only discussed in the context of clinical trials, but should be recommended for any deployment of neurotechnology. Furthermore, recommendations could be divided into (a) things Member States should support, promote and/or fund, (b) things Member States should regulate, and (c) things Member States should prohibit.

**14.a. Are the policy areas adequately described?**

- ○ Yes
- ○ No
- ○ No opinion

**14.b. If you replied "no" to the previous question, please provide concrete suggestions.**

Related to our response to 13.b, the structure and organisation of the recommendations makes it difficult to assess the policy areas individually. Many of the recommendations across policy areas should be cross-cutting, and it is unclear whether they are intended to be. Additionally, an introductory section could added that reiterates that neurotechnologies and neural data are

and should continue to be subject to all existing regulations, including on privacy and consumer protection, regardless of the impacted group or specific use case/context and irrespective of the source of acquisition of those neurodata or the type of organization involved in collecting the neurodata.

**15.a. Are the policies and recommendations described in Section V in line with the values and principles of Section IV?**

- ○ Yes
- ○ No
- ○ No opinion

**15.b. If you replied "no" to the previous question, please explain why.**

n/a

**16.a. Would you consider that the policies and recommendations in the document properly address the need for equal access to the technological developments both inside the country, as well as between countries?**

- ○ Yes
- ○ No
- ○ No opinion

**16.b. If you replied "no" to the previous question, please provide concrete suggestions.**

n/a

**17.a. Is there anything in this section with which you would fully disagree?**

- ○ Yes
- ○ No
- ○ No opinion

**17.b. If you replied "yes" to the the previous question, please explain what part and why.**

n/a

**18.a. Are there important aspects or applications of neurotechnology not covered?**

- ○ Yes
- ○ No
- ○ No opinion

**18.b. If you replied "yes" to the the previous question, please specify:**

The document does not discuss the potential and current applications of neurotechnologies in law enforcement, border control, and judicial systems. As the use in these sectors is based on scientific research, these applications fall within the mandate of UNESCO and should be included in the recommendation.

**19.a. Are all relevant actors identified in the draft text?**

- Yes
- No
- No opinion

**19.b. If you replied "no" to the previous question, please specify which should be added or removed:**

Not enough is said about the role of commercial, for-profit development and use of neurotechnologies, which often fall outside the scope of existing research ethics governance frameworks. The mention of 'industry' in Section V.3.1 is not sufficient, as the section only relates to clinical trials, not R&D for commercial products and services. For example, Member States should adopt measures to ensure that any neurotechnology research, whether public or private, is subject to strict research ethics protocols as described in Section V.3. Additionally, the language in para 140 should apply outside of the health sector; all specific mention of 'patients' should be replaced with 'human research subjects'.

**20.a. Are the identified policies and recommendations adequate to promote diversity and non-discrimination?**

- Yes
- No
- No opinion

**20.b. If you replied "no" to the previous question, please provide concrete suggestions.**

n/a

**21.a. Do the proposed policies and recommendations adequately address the gender perspective?**

- Yes
- No
- No opinion

**21.b. If you replied "no" to the previous question, please provide concrete suggestions.**

n/a

**22.a. Do you think that the way the technologies are developing would have a differentiated impact depending on gender?**

- Yes
- No
- No opinion

**22.b. If yes, is this adequately addressed in the recommendations proposed in this document?**

n/a

**23.a. Do the proposed policies and recommendations on neurotechnology contribute to the protection of vulnerable populations?**

- ○ Yes
- ○ No
- ○ No opinion

**23.b. If you replied "no" to the previous question, please provide concrete suggestions.**

n/a

**24.a. Do the proposed policies and recommendations address neurodiversity adequately?**

- ○ Yes
- ○ No
- ○ No opinion

**24.b. If you replied "no" to the the previous question, please provide concrete language.**

n/a

**25.a. Are the responsibilities of all relevant actors, including the private sector, properly reflected in the document?**

- ○ Yes
- ○ No
- ○ No opinion

**25.b. If you replied "no" to the previous question, please explain further:**

See response to 19.b.

**26.a. Are the proposed recommendations ensuring accountability of the different actors throughout the lifecycle of the technology?**

- ○ Yes
- ○ No
- ○ No opinion

**26.b. If you replied "no" to the previous question, please explain why.**

As the recommendations are not organised clearly (see response to 13.b), it is difficult to assess. One omission relates to recommendations for accountability when a private actor no longer exists or provides updates to a neurotechnology device that is implanted (e.g. SecondSight retinal sensors no longer provide support, as the company faces bankruptcy). Member States should ensure strong measures are in place to ensure consumers are protected from harm, to require contingency plans be put in place to ensure continuity in providing the service, and to hold companies liable for causing harm.

**27.a. Is there any contradiction or tension between the legal framework of your country and the policies and recommendations proposed in the document?**

- Yes
- No
- No opinion

**27.b. If you replied "yes" to the previous question, please provide specific examples.**
n/a

**28.a. Do you think the legal framework of your country is effectively addressing the challenges posed to human rights raised by neurotechnology?**
- Yes
- No
- No opinion

**28.b. If you replied "no" to the previous question, please provide concrete suggestions on how to improve existing laws.**
n/a

**29.a. Does the Recommendation adequately reflect the need for international cooperation to address the technical gaps?**
- Yes
- No
- No opinion

**29.b. If you replied "no" to the previous question, please explain further:**
n/a

**30.a. Are future developments of the technology sufficiently taken into consideration?**
- Yes
- No
- No opinion

**30.b. If you replied "no" to the previous question, please explain further:**
In general, the document conveys a sense that “advancement of neurotechnology is a major source of potential benefits” without seriously questioning the actual limitations of the technology. For example, the document does not address the group-to-individual (G2i) problem (referring to the challenge of determining an individual’s assessment from group data), which has a significant impact on the accuracy of inferences made from group-level (i.e. aggregated) neural data. The recommendations should urge Member States to take more caution in promoting the use of neurotechnologies until more robust research is done and should recommend prohibitions (or strict regulation) on neurotechnology in certain sectors, e.g., law enforcement and judicial systems, educational assessment, insurance.

**31.a. Are there any proposed recommendations that you would consider too restrictive?**

- Yes
- No
- No opinion

**31.b. If you replied "yes" to the previous question, which one(s)? Please propose concrete rewording.**

n/a

**32.a. Are there any proposed recommendations that you would consider too permissive?**

- Yes
- No
- No opinion

**32.b. If you replied "yes" to the previous question, which one(s)? Please propose concrete rewording.**

Recommendations in Section V.4 related to data policies should be stronger. Recognising the inherent risks to human rights, well-being, privacy and confidentiality associated with the collection and use of neural data, neural data should be classified by default with the highest level of protection (e.g., 'special category' data under GDPR). Member States should create legal regimes that recognise that individuals own their neural data and guarantee individuals the associated rights to control who can access, use, profit from, sell, etc their neural data.

# Implementation

**33. Would you have any specific suggestions on how these recommendations could be implemented and have impact on the ground? Please specify:**

1. One of Unesco's greatest strengths is the promotion of human rights across all sectors, particularly in science. This document should be promoted within a human rights framework, as member states have already committed to the UDHR and one or more human rights treaties
2. DISSEMINATION: Creating stronger awareness is essential as many of the themes of this recommendation are not familiar to the general public, regulators, or even the scientific community. Different actions could be targeted specifically to these communities and to stakeholders most likely to be impacted by the current and future use of neurotechnology.
3. ETHICAL IMPACT ASSESSMENT: UNESCO should recommend that Member States require or support conducting impact assessments pre-deployment to guide developers and/or deployers of neurotechnology to work in collaboration with multi-disciplinary experts and affected communities to identify and assess actual and potential impacts associated with the short, medium, and long-term deployment of neurotechnologies. UNESCO could provide a template for neurotechnology EIA, similar to the one provided for AI.

4. NEUROTECHNOLOGY MONITORING: UNESCO could establish a monitoring body that will collect and make publicly available essential information about neurotechnologies. Member states' contribution to the collection should be encouraged (perhaps included as part of the recommendation). Sample information to be included in the publicly accessible collection:
    a. Neurotechnology in use or being developed
    b. Experts in various fields of neurotech
    c. Incidents related to the use of neurotech
    d. Regulations developed or being developed for neurotech
    e. Tools, metrics, vocabulary, … related to neurotech

Additional comment: As multi-disciplinary researchers concerned about the unregulated deployment of potentially harmful technologies, we welcome the opportunity to contribute to this critically-important global dialogue on the ethics of neurotechnologies. We would be pleased to provide any elaboration on our comments. To contact: Dr. Claudia Roda (croda@aup.edu); Dr. Susan Perry (sperry@adu.edu); Dr. Tara White (tara_white@brown.edu); Nicole Santiago (nsantiago@aup.edu)