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Global Consultation Submission First Draft Text of UNESCO Recommendation on Ethics of Neurotechnology

12 July 2024

Dr. Mariagrazia Squicciarini Chief Executive Office Social and Human Sciences Sector UNESCO

Dear Dr. Squicciarini:

I am writing to complete our submission for the global consultation on the UNESCO Ethics of Neurotechnology draft due today. We greatly appreciate the opportunity to respond to this important consultation.

We are contacting you as we understand that your office is providing support to the AHEG and there was no email contact information provided on the web pages associated with this call.

The reason for this supplementary submission proceeds from limitations we encountered in using the online form, which we appreciate is the preferred channel.

These limitations include the inability to carry over to the online form any formatting [such as italics, text bolding, indention, colour, etc.] from our working draft, meaning that UNESCO staff would not be able to properly interpret our intent at numerous points. Further, our approach for some questions led us to include a number of paragraphs from the draft for reference, challenging the length limits established for various questions.

We have provided a WORD and PDF version to assist with processing, and hope that your office will forward this email to the appropriate team for processing.

Also, as a courtesy, I copy here colleagues who we understand are either co-chairs or the rapporteur in the Bureau of the AHEG.

Thank you in advance...we would greatly appreciate confirmation of successful receipt and appropriate disposition of these attachments.

drc

David R Curry, MS
President & CEO
GE2P2 Global Foundation

Cc: Drs. Herve Chneiweiss, Nita Farany, Pamela Andanda

Global Consultation Submission First Draft Text of UNESCO Recommendation on Ethics of Neurotechnology Questionnaire

A. Definition and Scope

In this section, we would like you to tell us more about your views and perceptions regarding the definition of neurotechnology and scope of the <u>first draft of UNESCO's Recommendation</u>.

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?

Choose one of the following answers

- Yes
- <u>No</u>
- No opinion
- 1.b. If you replied "no" to the previous question, please suggest alternative wording.

We assess that there are important dimensions which should be included in the definition on neurotechnologies which, for the most part, are alluded to later in the document. Our proposed definition includes such dimensions as below [see bolded text]:

"...devices and procedures used to understand and/or influence, access, monitor, assess, emulate or modulate the structure and/or function of the nervous systems of human beings and other animals, and which may also result in changes to other organs and systems, and potentially affect cognitive autonomy or agency, decision-making and/or behaviours..."

Please see reference to these dimensions in paragraph 27:

.27. With its increasing ability to influence neural processes and mental, neurotechnology poses potential threats to personal identity and agency, raises worrying prospects of (i) implicit coercion due to power imbalance and competitive disadvantage (e.g., in the workplace), (ii) modulation of individual behaviours in unexpected, unwanted, and/or unconsented ways.

We appreciate the integration of life-cycle thinking in this definitional section. We assess that including specific reference to gender would strengthen the sense of "diversity" in 10 along with other modes of access, equity, engagement, recognition and benefits sharing.

- .9. Whole life cycle. Neurotechnology should be considered from the early stages of research, design and development to deployment and use, including maintenance, operation, trade, financing, monitoring and evaluation, validation, end-of-use, disassembly, and termination. (as referenced in the Recommendation on the Ethics of Artificial Intelligence).
- .10. Considering the whole life cycle of neurotechnology is a way of identifying the actors that are involved in any stage, in addition to ensuring the protection of the general public and diversity in teams and populations, would also be involved in every stage, along with the technical and professional specialists.

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

- Yes
- No
- No opinion
- 2.b. If you replied "yes" to the previous question, please explain:

We recognize the importance of precision in articulating the scope for the draft and comment on specific paragraphs in this section as below:

.11. The use of neurotechnology may fundamentally affect human rights by directly affecting the nervous system in aspects such as perception and motor or mental activities.

In terms of human rights, the scope can be more specific about the interface to human rights. This paragraph might well address three human rights aspects (for example, as highlighted by the Council of Europe): the right to mental privacy, the right to mental integrity, and the freedom of the human mind, thereby preventing external manipulation. We do note the expansive treatment of these ideas in later paragraphs 22, 23 and 25, as well as across section *IV.1.1. Respect, protection and promotion of human rights fundamental freedoms and human dignity.*

12. This Recommendation has been undertaken in light of the rapid development of neurotechnology and its convergence with other technologies including spatial computing, XR, and artificial intelligence.

While we welcome the reference to other technologies as above, we urge consideration of adding other technologies that can be construed as intersecting with neurotechnologies in the near-term. We assess that genomics is a credible example of such an convergence and suggest that the closing sentence could usefully conclude as below:

"...other technologies including spatial computing, XR, artificial intelligence and genomics."

14. This Recommendation focuses on humans only, although many important considerations apply to animals are beyond its scope.

We recognize that difficult decisions around scope must be made, but we are concerned that remaining "silent" on neurotechnologies involving non-human animals – without referencing what parallel initiatives may be addressing this area, or recognizing that there is no parallel initiative – is less that fully effective and responsible.

3.a. Do you think the scope is too broad?

Choose one of the following answers

- Yes
- <u>No</u>
- No opinion
- 3.b. If you replied "yes" to the previous question, please explain why.

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?

Choose one of the following answers

- Yes
- No
- No opinion
- 4.b. If you replied "no" to the previous question, please suggest concrete wording:

We are concerned that the intersection between neurotechnologies and AI is not addressed comprehensively or adequately, quite apart from "encompassing well the speed and depth of developments...". This assessment is based, in part, by the inventory of paragraphs from the Draft below:

- .28. The convergence of advances in AI with neurotechnology raises particular risks related to algorithmic bias, lack of transparency, and risks to mental privacy of individuals. It increases the possibility of manipulation and profiling.
- .50. Neurotechnology, in its interface with other technologies such as artificial intelligence (AI) should not be used to profile, target or exploit people based on their characteristics. This use should be particularly avoided/prohibited in the context of vulnerable individuals and groups.
- .155. Validation of AI algorithms in neurotechnology research should include rigorous testing for biases, as well as measures to enhance explainability and transparency. Debiasing techniques should be employed to mitigate any biases present in AI models used in neurotechnology applications.
- .163. In response to rapid advancements in neurotechnology and their convergence with other technologies including AI, spatial computing and immersive technologies, Member States should adopt agile regulatory frameworks and regulatory sandboxes.
- .166. Member States should consider specific guidelines for the ethical use of neural and cognitive biometric data in AI development and research, including consent procedures for uses of neural data in training AI models,
- 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? Choose one of the following answers

- No
- No opinion
- 5.b. If you replied "no" to the previous question, please suggest alternative wording.

B. Approach

In this section, we would like you to tell us more about your views and perceptions regarding the approach adopted in the first draft of UNESCO's Recommendation.

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

Choose one of the following answers

- Yes
- No
- No opinion
- 6.b. If you replied "no" to the previous question, please explain:

While paragraphs in this section recognize a broad range of ethical challenges, we assess that the treatment is not exhaustive and does not adequately articulate the implications of the paragraphs below.

We assess that these paragraphs suggest, and arguably should be explicit about, the range of actors – member states, non-state actors, commercial entities, etc. – that have or are likely to gain the capability to develop, control and utilize various neurotechnologies to further national and/or geopolitical agendas. These paragraphs also fall short in articulating the ethical issues associated with military/defense uses of neurotechnologies.

We note that none of these terms appear in the draft: "military" "defence/defense" "conflict" "geopolitical"

We urge the AHEG to explore and reflect further on these areas in future drafts.

- .27. With its increasing ability to influence neural processes and mental [?states], neurotechnology poses potential threats to personal identity and agency, raises worrying prospects of (i) implicit coercion due to power imbalance and competitive disadvantage (e.g., in the workplace), (ii) modulation of individual behaviours in unexpected, unwanted, and/or unconsented ways.
- .28. The convergence of advances in AI with neurotechnology raises particular risks related to algorithmic bias, lack of transparency, and risks to mental privacy of individuals. It increases the possibility of manipulation and profiling.
- .30. The temptation to embrace neuroenhancement may lead to the risk of not only unexpected damage to the nervous system but also to amplified biological- and technologically-based inequalities within society, threatening the very concept of humanity.
- .31. Non-inclusive technological development and standardisation may drive a trend toward a homogenization process and the dominance of neurotypicality and capacities that may represent supplementary threats to cultural and collective identity.
- .32. Neurotechnology-related risks may emerge both at the individual and group level. Group-level risks include group manipulation and group-level privacy and discrimination based on the identification of common neurobiological features.

Finally, we suggest that a new paragraph be considered which speak to the imperative to continuously monitor and refine this section as both positive and negative synergies emerges at the intersections between and among neurotechnologies, AI, genomics and other disruptive technologies and the larger context outside these technologies.

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

Choose one of the following answers

- Yes
- No
- No opinion

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

As a complement to *III.3 Ethical Challenges in neurotechnology*, this section does articulate important concepts and areas of concern. However, we do note that paragraphs 21-25 are less disciplined in their construction and argument than other sections of the draft, sometimes verging on questionable, ungrounded and/or specious assertions.

.22. As the coordinating centre of behaviour and cognitive-affective processes, any intervention involving the nervous system is of particular ethical, societal and human rights significance. Furthermore, important ethical principles such as self-determination, agency, responsibility, personal autonomy, relational intelligence, and empathy are deeply rooted in mental functions.

We do not understand the sense intended by the text that ethical principles "are deeply rooted in mental functions" – if the listed elements are indeed "important ethical principles."

.23. Human beings are rational and social animals: the nervous system enables and supports the cognitive and affective capacities that make us human. Our highly complex nervous system is also a fundamental factor in our ability to conceive values and care about those values. It enables us to act as moral agents, be responsible for our actions, cooperate with others, deliberate about collective decisions, feel empathy, and develop our personality.

This argumentation seems to be laying out a unique theory of humanness, including the role of our "highly complex nervous system" as enabling us to act as moral agents, etc. This all may be "true" albeit trivially so. We are concerned that these paragraphs are not contributing to the draft and should be reconsidered or deleted.

.24. From a biological perspective, the development of the nervous system is decisive for the belonging of the individuals to the human species. However, to truly embody humanity, the human brain requires interactions with other human brains. These interactions encompass the acquisition of both verbal and non-verbal languages, as well as the processes of learning and memory. Encapsulated in the philosophy of ubuntu, we can affirm: "I am because we are." In this way we can recognize the agency also in its collective dimension as part/result of a broader sense of individual existence in their belonging to a community.

This paragraph continues articulation of the unique theory of humanness as above, adding notions about what is "decisive for belonging to the human species", and what the human brain "requires." This is unsettling and sophomoric. Further, given the global audience for these recommendations, we are

surprised by the reference to a noble, but clearly regional, cultural construct [ubuntu] as part of this line of argument. We urge reconsideration of its inclusion in future drafts.

.25. This Recommendation embraces a human-centred approach through fundamental ethical principles including but not limited to self-determination, freedom of thought, responsibility, privacy, personal and collective identity, fairness, trust, respect, reciprocity, and justice. Furthermore, it should be based on the promotion and protection of human rights.

We underscore here our concern with the imprecision of this section overall. Here we have a list of "fundamental" ethical principles, not matching the "important" ethical principles listed a few paragraphs earlier in 22 above.

C. Values and principles

In this section, we would like you to tell us more about your views and perceptions regarding the values and principles adopted in the <u>first draft of UNESCO's Recommendation</u>.

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

Choose one of the following answers

- Yes
- No
- No opinion

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

This section – comprising 30+ paragraphs – certainly references "values" in a number of contexts, with varying precision and grounding. We are concerned that this question and the next [8.a and 9.a] are sweeping in asking if we "endorse" the embedded values and less than fit-for-purpose for this global consultation. That said, while we do endorse some/many of these "values" we comment on specific paragraphs as below.

.35. The inviolable and inherent dignity of every human constitutes the foundation for the universal, indivisible, inalienable, interdependent and interrelated system of human rights and fundamental freedoms. Therefore, respect, protection and promotion of human dignity and rights as established by international law, including international human rights law, is essential for the use of neurotechnology. Human dignity relates to the recognition of the intrinsic and equal worth of each human being, regardless of race, colour, descent, sex, gender, age, language, religion, faith, or beliefs, **neurobiological and mental characteristics (features)**, political opinion, national origin, ethnic origin, social origin, economic or social condition of birth, or disability and any other grounds.

We assess that the inclusion of this bolded phrase above requires and deserves some specific definition and brief discussion in the text. We may have limited literacy here but are entirely unclear what elements would be including in "mental characteristics [features]".

.37. Particular, but not exclusive focus should be devoted to the promotion and protection of the specific human rights relating to a person's brain and mental experiences (sometimes referred to as 'neurorights' and/or 'cognitive liberty' (IBC 2021, 17)). This bundle of rights should be contextualized within the context of existing human rights to further strengthen, not diminish, the international human rights framework. To do so, balanced assessments of rights inflation and deflation need to be conducted and

deliberative processes need to be based on conceptual clarity, rigorous doctrinal analysis and democratic consensus.

We find this paragraph to be unhelpfully jargon-laden, invoking notions of rights inflation/deflation and deliberative processes ["doctrinal analysis" etc,]. We observe that this text does not contribute to the utility of the draft and should be re-written.

.39. The use of neurotechnology in the care or assistance of vulnerable people across the entire lifespan of people in vulnerable situations, including but not limited to children, older persons, persons with physical and cognitive disabilities or the ill, should never objectify them, nor undermine their dignity, human rights or fundamental freedoms.

We assess that the reference to "care and assistance" above should be enhanced to include the concept of functioning (the third health indicator alongside mortality and morbidity). Human functioning integrates biological health (the bodily functions and structures that constitute a person's intrinsic health capacity) and lived health (a person's actual performance of activities in interaction with their environment). It is key to valuing health both in relation to individual well-being and societal welfare.

.42. In contexts requiring resource allocation, the benefits to the worse off (including but not restricted to people with neurological disorders, mental illness and/or physical and cognitive disability) should be given priority.

We observe in this paragraph the default to prioritarianism in terms of distribution of limited or scare goods/resources. This approach is only one option and potentially not the best or most ethically resilient. This, indeed, *is* an ethical principle but is not referenced elsewhere in the draft or in the various lists of "important or "fundamental" ethical principles.

.44. Scientific research and development focusing on neurotechnology should be transparent, comply with the best standards of evidence and aligned with international principles of responsible conduct of research and scientific integrity. This requires, among other things, clinical trials involving neurotechnology applications comply with guidelines on the pre-registration of trials, fair selection of participants, approval by independent ethics committees and responsible and transparent communication of the scientific findings.

We observe the reference to "best standards of evidence and aligned with international principles of responsible conduct of research and scientific integrity" – suggesting that there is in place a stable, complete, coherent architecture of standards and principles. We are concerned that this depiction is imprecise and unhelpful. The second part of the paragraph notes a few elements one would include in such an architecture but does not include reference to high methodological quality.

.48. Respect for diversity and inclusivity must be upheld at every stage of the lifecycle of neurotechnology. Special consideration should be given to minority groups and underrepresented voices.

We assess that this paragraph would be stronger with the addition of specific reference to persons with disabilities, as a group at potentially higher risk of experiencing harmful use of neurotechnology.

.51. Given that widely recognized neurotechnological innovation largely occurs in the urban well-resourced sector, specific attention to underserved and historically marginalized people is vital to protect against bias, continuous disparities in healthcare, persecution, stigma, neglect, and disrespect.

Technological colonization through loss of culture and heritage, therefore, is a substantive threat that must be avoided.

We note the reference in the closing sentence to "technological colonization though loss of culture and heritage." As this is the only use of the term "colonization" in the draft overall, and the mechanisms of cultural and heritage loss are not discussed further here or elsewhere in the draft, we are concerned about its grounding and contribution to the draft.

.58. The use of neurotechnology should never undermine freedom of thought and mental selfdetermination, and mental privacy especially in contexts where the refusal to use the technology may generate a competitive disadvantage or a risk of implicit coercion.

We note here the important reference to "refusal to use the technology" as a "value" and its potential implication regrading competitive disadvantage and coercion. If anything, this paragraph should be extended and strengthened. We see other instances of these ideas at other points in the draft.

- .67. The following points outline additional core areas of focus:
- **.a. Ethics and Oversight:** develop stringent ethics review processes for industries currently lacking oversight. This should include international regulations to standardize reporting of device complications, failures, and feedback to ensure continuous improvement.
- **.b.** Accountability for Violations: establish robust regulatory frameworks to hold violators accountable for ethical breaches, such as unauthorized data use, disregard for privacy, or inappropriate data storage. These frameworks should be enforced by respective governmental and state bodies to maintain high ethical and legal standards in the use of neurotechnology.
- **.c.** Respect for Indigenous people and lands: ensure the protection of and consultation with Indigenous people with respect to Indigenous lands (mining) and rights (knowledge, protection of communal rights and privacy) in the extraction of mining materials for neurotechnology from lands with scarce resources.

We largely agree with the spirit of these sweeping "additional core areas of focus" but are concerned that [a] and [b] are not tethered to any practical reality or appreciation for the complexity of what is indicated. For example, the referenced development of "stringent ethics review processes for industries currently lacking oversight. This should include international regulations to standardize reporting of device complications, failures, and feedback to ensure continuous improvement" is, quite probably, a decade-long process at least and is simply not responsive to the velocity of neurotechnology development and impact. Indeed, where does the authority lie to assure ethics and oversight for industries "lacking oversight" and secure accountability for "violations"?

9.a. Is there a value that is missing?

Choose one of the following answers

- Yes
- No
- No opinion

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

10.a. Would you endorse the principles identified in the document (p. 12-14)? Choose one of the following answers

- No
- No opinion

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

We continue to react negatively to questions about "endorsement" of specific, extended sections of the text [20+ paragraphs here] given that we are still at Draft 1. We share observations and comments on specific paragraphs as below:

.73. People should have the right to self-determination to make free, informed, and voluntary decisions about whether they want to use a certain neurotechnology application or refuse to do so. These individual decisions, however, should be balanced against considerations relating to societal and collective wellbeing.

This paragraph combines an important and unsurprising opening sentence around consent, etc. but closes with a sentence that raises an unquantified counterbalance where such individual decisions "should be balanced against considerations relating to societal and collective wellbeing." The full draft does not make any further reference to "collective wellbeing" while "societal well-being is referenced further only with regard to member states establishing regulatory frameworks the promote it [206-207].

.91. From an ethical perspective, it is important to balance the potential benefits of enhancing cognitive function through neurotechnology for early diagnosis, instruction, education, and continuous learning with a commitment to the holistic development of the child. This includes nurturing their social life, fostering meaningful relationships, and promoting a healthy lifestyle encompassing nutrition and physical activity.

We note with concern that 91 sets up an unquantified and ungrounded tension. It suggests that there is some broad societal acceptance and support for enhanced cognitive function [referencing instruction, education, continuous learning (via neurotechnologies)] which needs to be balanced with "holistic development of the child" [referencing social life, healthy lifestyle, etc.]. This area is, in our assessment, a key flashpoint for societal debate, not a "balancing act." This paragraph and other references to cognitive enhancement requires examination.

11.a. Is there a principle that is missing?

Choose one of the following answers

- Yes
- No
- No opinion

11.b. If you replied "yes" to the previous question, please provide concrete language.

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

Choose one of the following answers

- 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.

D. Areas of policy actions/recommendations

In this section, we would like you to tell us more about your views and perceptions regarding the proposed areas of policy action and recommendations addressed in the <u>first draft of UNESCO's</u> Recommendation.

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

Choose one of the following answers

- Yes
- No
- No opinion

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

14.a. Are the policy areas adequately described?

Choose one of the following answers

- Yes
- No
- No opinion

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

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

Choose one of the following answers

- Yes
- No
- No opinion

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

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?

Choose one of the following answers

- Yes
- No
- No opinion

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

We assess that while member state actions and imperatives are broadly articulated, the cross-boundary/regional/global dimensions of their role – and the role of other stakeholders at that level – are too limited.

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

Choose one of the following answers

- Yes
- No
- No opinion
- 17.b. If you replied "yes" to the the previous question, please explain what part and why.

18.a. Are there important aspects or applications of neurotechnology not covered? Choose one of the following answers

- Yes
- No
- No opinion

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

We note the inclusion in the draft of important language referencing "design" but urge inclusion and treatment of the concept/principle of "universal design" which strives to ensure that products/ technologies, etc. are accessible to people with a wide range of abilities, disabilities, and other characteristics.

We note the following selected paragraphs for context:

- .43. Responsible scientific research and innovation focusing on the **design**, **development and implementation of neurotechnology is essential** for the promotion of human health and wellbeing and should aim at the promotion of human rights.
- .49. Individuals and groups should have the freedom to make lifestyle choices, express beliefs and opinions, share personal experiences, and **participate in co-designing technologies** without restrictions.
- .102. Member States should fund research and development grants focused on creating user-friendly assistive neurotechnology tailored for children with disabilities. These projects should **involve end-users in the design process** to ensure the technologies meet their specific needs.
- .107. Member States should establish **enforceable guidelines for neurotechnology design sensitive to the usability needs** of older adults, carefully considering human-computer interface factors for usability (such as fonts, buttons, and colour) for enhanced visual and auditory cues.
- .121. Member States should develop incentives for companies and research institutions to create neurotechnology specifically designed to improve the quality of life and functional independence of people with disabilities. This could include tax breaks, grants, or expedited regulatory reviews and approvals for technologies that offer significant advancements in mobility, communication, or daily living for disabled individuals.

.164. Member States should support the development and implementation of technological innovations and **design standards for neurotechnology that prioritize mental privacy,** such as state-of-the-art encryption, secure databases with multi-factor authentication, cutting-edge anonymization techniques, and edge-processing and storage (processing and storing data closer to where it's being generated), leading to greater action-led results in real time and storage of neural data.

.167. Member States should incentivize neurotechnology manufacturers to **prioritize privacy and ethics by design**, requiring the incorporation of privacy-preserving technologies as default features in their devices. This proactive approach ensures that privacy protections are embedded into the design and functionality of neurotechnological devices from the outset, enhancing user privacy and data security. Manufacturers should implement state-of-the-art encryption, secure authentication mechanisms, and anonymization techniques to safeguard neural and cognitive biometric data and protect users' mental privacy.

.218. Member States should develop oversight mechanisms to prevent the use of neurotechnology to drive compulsive or addictive use, particularly if they target neural reward circuits to alter consumption behaviours. Such regulations should mandate clear labeling of risks, enforce game design standards that discourage compulsive use of gaming or digital recreational platforms combined with neurotechnology, to promote healthy, balanced use, especially among children and vulnerable populations.

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

Choose one of the following answers

- Yes
- <u>No</u>
- No opinion

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

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

Choose one of the following answers

- Yes
- No
- No opinion

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

We urge inclusion of discussion around social determinants of health and utilization of technical language in the text which address non-discrimination and diversity, such as the *UN Convention on the Rights of Persons with Disabilities*.

We note that section titled *V.1.4 People with Physical Disabilities* does not seem appropriate given that this section references persons with sensory and physical impairments, not all of which lead to the experience of disability. Similarly, the section titled *V.1.5 People with Mental Health Disabilities* does not seem appropriate given that the section refers to people with mental health conditions, not all of which lead to the experience of disability.

While it is important to highlight the specific disadvantage faced by people with disabilities, to single out two groups (people with physical and mental disabilities) provides a reductive overview of the experience of disability (intellectual, physical, sensory and mental).

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

Choose one of the following answers

- Yes
- No
- No opinion

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

The draft would be strengthened by addressing intersectionality.

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

Choose one of the following answers

- Yes
- No
- No opinion

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

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

Choose one of the following answers

- Yes
- No
- No opinion

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

Further to the extensive treatment of informed consent and assent across the document, particular attention should be paid to the informed consent of persons with disabilities, especially intellectual disabilities, especially where the neurotechnology intervention may be supportive or represent a potential enhance to cognitive function.

24.a. Do the proposed policies and recommendations address neurodiversity adequately? Choose one of the following answers

- Yes
- No
- No opinion

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

We assess that "neurodiversity" as a construct will benefit from much additional research and evidence in the years ahead.

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

Choose one of the following answers

- Yes
- No
- No opinion

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

We observe the extensive number of instances in the draft which lead with "member states should" and the absence of any comparable treatment of action recommendations/imperatives for other stakeholder groups. Indeed, some 150 paragraphs in the text reference actions member states should engage. While some paragraphs do reference other stakeholders, it is through the lens of what the member state should be undertaking. See below a rudimentary text search analysis trying to identify other stakeholder references in the draft.:

Member states should... approx 250 paragraphs [93-240]

Universities should.. :: 0
Civil society should... :: 0

Patients/Patient groups should... :: 0

Sponsors should... :: 0
Industry should... :: 0

Manufacturers are encouraged to... :: 1 [179]

Developers are encourage to... :: 1 [179]

.179. Manufacturers, developers, and researchers are encouraged to communicate responsibly concerning neurotechnology to prevent sensationalism, particularly in the portrayal of capabilities such as "mind-reading" or "telepathy." They should collaborate in the co-creation of accurate, precise, and accessible language and terminology for discussing neurotechnology that involves stakeholders from diverse backgrounds to ensure that the language used is inclusive, non-stigmatizing, and accurately reflects the technologies' capabilities and limitations. Additionally, they should develop common standards for reporting complications, failures, feedback, and successes.

We recall our response to the UNESCO public consultation leading to <u>Guidelines for the governance of digital platforms: safeguarding freedom of expression and access to information through a multi-stakeholder approach</u> [2023] which articulates specific roles and action imperatives across the same set of stakeholders in a parallel disruptive technology area. The treatment there may be helpful for further refinement of this draft.

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

Choose one of the following answers

- No
- No opinion

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

Obviously "no"...see question 25 above.

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

Choose one of the following answers

- Yes
- No
- No opinion

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

28.a. Do you think the legal framework of your country is effectively addressing the challenges posed to human rights raised by neurotechnology?

Choose one of the following answers

- Yes
- No
- No opinion

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

29.a. Does the Recommendation adequately reflect the need for international cooperation to address the technical gaps?

Choose one of the following answers

- Yes
- No
- No opinion

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

We assess that the draft does not robustly engage this issue.

30.a. Are future developments of the technology sufficiently taken into consideration?

Choose one of the following answers

- Yes
- No
- No opinion

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

We assess this to be a non-sensical question.

31.a. Are there any proposed recommendations that you would consider too restrictive? Choose one of the following answers

- Yes
- No
- No opinion

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

32.a. Are there any proposed recommendations that you would consider too permissive? Choose one of the following answers

- Yes
- No
- No opinion

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

E. Implementation

In this section, we would like you to tell us more about your views and perceptions regarding the future implementation of UNESCO's Recommendation.

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

We do note a section in the draft title *VI. Implementation* which has no text but notes "to be completed at a later stage". We organize our response to question 33 under thematic areas as below.

Stakeholders Roles/Imperatives

We recognize the extraordinary number of paragraphs in the draft [approx 150] leading with "Member states should..." Across this range, there are governance, policy, regulatory and normative actions of varying complexity and nuance. None of these recommendations include discussion of precedents, resource requirements, implementation strategies, likely time to completion, etc.

We also recognize that there are literally no recommendations of substance addressing other key stakeholders: civil society, industry/manufacturers/developers, research sponsors, patients/patient groups, others.

It is unclear to us how this imbalance might be corrected such that the most strategically important recommendation can successfully be implemented through collaborative effort across the stakeholder ecology.

Global Governance/Stewardship

We note that global governance and stewardship of the neurotechnology space is not referenced in the text. The term "stewardship" does not appear in the draft, and the term "governance" appears only twice, and not in the sense of a global governance remit for any organization or body, existing or new.

- .170. Member States should ensure that the principles of autonomy, self-determination, should be paramount in the governance of neurotechnological enhancements.
- .173. Effective communication and comprehensive stakeholder engagement (including community engagement) are essential in the development, deployment, and governance of neurotechnology.

This is troubling as it mirrors similar gaps in global governance and stewardship roles for other rapidly evolving, disruptive technologies including AI and gene editing, for example. These roles would presumably include articulation and harmonization of norms over time and have oversight for enforcement mechanisms against those norms among other responsibilities.

Of course, UNESCO itself is playing an important role in this regard by convening expertise, stakeholders, member states, etc. to develop these recommendations. But we do not see discussion of any kind of an interagency collaboration, perhaps involving OHCHR, WIPO, WHO, ILS, etc.

Standards

Neurotechnology is similar to other rapidly emerging/evolving areas where development and implementation of "standards" inevitably trails the leading edge of innovation, often with troubling implications.

We are concerned that the term "standards" – appearing 28 times throughout the draft – is often used without adequate precision and leaves an impression that developing de novo standards is "straightforward" without any acknowledgement of the multi-year processes involved. In some cases, the term is used in a way that suggests that relevant standards are already in place, where we do not recognize that this is the case.

The inventory below is indicative [not exhaustive] of these issues, which represent a significant challenge to implement.. We bolded selected text for convenience:

- .19. The objectives of this Recommendation are: (i) to guide the actions of individuals, groups, communities, institutions and private sector companies to ensure the embedding of ethics in all stages of neurotechnology development and use (ii) to provide a universal framework of values, principles and actions to guide Member States in the formulation of national legislation, policies or other instruments regarding neurotechnology, consistent with international standards...
- .65. This involves **adherence to regulatory and professional standards**, ensuring that all activities respect personal privacy, dignity, and environmental sustainability. This includes ethical safety measures and the integration of designs that facilitate disassembly, recycling, and recovery of precious materials at the end of the product's lifecycle.
- .67.b. Accountability for Violations: establish robust regulatory frameworks to hold violators accountable for ethical breaches, such as unauthorized data use, disregard for privacy, or inappropriate data storage. These frameworks should be enforced by respective governmental and state bodies to maintain high ethical and legal standards in the use of neurotechnology.
- .147. Member States should ensure their animal welfare laws align with the **latest ethical standards in research and industrial use**. They should support the development of tools that can assess distress and pain in experimental animals to minimize suffering. And should encourage that researchers adopt the 3R principles (replace, reduce, refine) in all animal research, with an emphasis on developing and following **common standards for implantable devices** that facilitate data reuse and reduce the number of animals used.

- .148. Member States should promote international cooperation to **develop common reporting standards** and protocols, particularly for implantable neurotechnology devices. This cooperation should aim to enhance the comparability and utility of research data globally, improving both the efficacy and ethical integrity of research.
- .159. In response to the rapid evolution of neurotechnology and its profound implications for mental privacy and self-determination, there is an urgent need for Member States to develop a robust framework to govern the collection, processing, and use of neural data. Recognizing the diversity of legal, technological, and cultural landscapes across the Member States, these policies aim to balance the promotion of technological innovation with the imperative to protect mental privacy, freedom of thought and self-determination, ensuring that neural and cognitive biometric data are managed in a manner that is ethical, sustainable, and aligned with global human rights standards.
- .164. Member States should support the development and implementation of technological innovations and **design standards for neurotechnology** that prioritize mental privacy, such as state-of-the-art encryption, secure databases with multi-factor authentication, cutting-edge anonymization techniques, and edge-processing and storage (processing and storing data closer to where it's being generated), leading to greater action-led results in real time and storage of neural data.
- .165. Member States should encourage ethical data sharing by establishing secure, data repositories for neural and cognitive biometric data used in research. These repositories should meet stringent cybersecurity, data privacy, and ethical use standards (including data minimization and purpose limitations), tiered access and other privacy-enhancing approaches. Developing and supporting global interoperability standards for neural and biometric cognitive data may likewise enhance cross-border research and cooperation.
- .172. Member States should encourage and incentivize "sandboxing" for safety testing neurotechnology under controlled conditions. This approach facilitates innovation while still safeguarding public health and safety by monitoring and evaluating the technologies before they are widely deployed. **Safety and efficacy standards** should be based on rigorous scientific testing and ethical analysis, particularly for technologies like brain stimulation and transcranial magnetic stimulation, which pose unknown long-term risks.
- ,178. Member States should develop regulatory frameworks and policies that require clear, accurate, and **ethical communication standards for neurotechnology**, grounded in data and evidence to prevent sensationalism or misinformation and promote understanding of the benefits, risks, and limitations of neurotechnology...
- .179. Manufacturers, developers, and researchers are encouraged to communicate responsibly concerning neurotechnology to prevent sensationalism, particularly in the portrayal of capabilities such as "mind-reading" or "telepathy." They should collaborate in the co-creation of accurate, precise, and accessible language and terminology for discussing neurotechnology that involves stakeholders from diverse backgrounds to ensure that the language used is inclusive, non-stigmatizing, and accurately reflects the technologies' capabilities and limitations. Additionally, they should develop common standards for reporting complications, failures, feedback, and successes.
- .210. Member States must enforce informed consent processes that are thorough and transparent across all neurotechnological interventions, ensuring that participation is fully voluntary and respects the privacy and autonomy of individuals. This principle should apply uniformly in various domains such as sports, arts, and 'neurohacking,' where robust standards

should safeguard against coercive use and respect athletes' and artists' individual autonomy, community interests, and intellectual property rights.

- .232. Member States should ensure that any use of neurotechnology in the judicial context is grounded in robust scientific evidence, implemented ethically and in accordance with human rights, and aimed at promoting public safety while protecting the rights and dignity of those involved. Any use of neurotechnology techniques within the judicial system must **adhere to international human rights standards**, ensuring respect for fundamental rights such as human dignity, bodily integrity, confidentiality of personal data, and the right to a fair trial. It is imperative that the use of such techniques is based on informed consent from the individuals concerned, with a clear understanding of the objectives, risks, and benefits of the intervention.
- .240. Member States should **collaborate to establish comprehensive standards for cybersecurity across all neurotechnology devices**. These standards should encompass hardware, software, and data security measures to protect against potential cyber threats, such as unauthorized access, data breaches, and malicious attacks.

Right to Refuse/Coercion

We note a number of instances in the draft which reference the right to refuse use of neurotechnology in whatever context and for whatever purpose, and complementary language around preventing "coercion" of any kind involving acceptance or use.

Given the potential implications of neurotechnology across individual development, cognitive liberty and exercise of agency and autonomy, we assess that this thematic area may well deserve more specific and higher profile discussion in the draft, anchored by ideas articulated across the paragraphs below [indicative, not exhaustive]. We bolded selected text for convenience:

- .27. With its increasing ability to influence neural processes and mental, neurotechnology poses potential threats to personal identity and agency, raises worrying prospects of (i) implicit coercion due to power imbalance and competitive disadvantage (e.g., in the workplace), (ii) modulation of individual behaviours in unexpected, unwanted, and/or unconsented ways.
- .58. The use of neurotechnology should never undermine freedom of thought and mental self-determination, and mental privacy especially in contexts where the **refusal to use the technology** may generate a competitive disadvantage or a risk of **implicit coercion**.
- .73. People should have the right to self-determination to make free, informed, and voluntary decisions about whether they want to **use a certain neurotechnology application or refuse to do so**. These individual decisions, however, should be balanced against considerations relating to societal and collective wellbeing.
- .95. Member States should protect the autonomy of children through informed consent and assent that is adapted to and respectful of age and decision-making capacity. Given substantial differences between consenting a child and an adult for research or clinical procedure related to variable patterns and rates of neurodevelopment, it is advised that **no predetermined minimum age of consent or refusal concerning medical treatments applies**. A capacity-based framework wherein researchers first defer to the judgment of minors deemed capable through standardized metrics has been a recommended approach.
- .98. Member States should ensure the protection of assent and consent from **social pressure**, **force or coercion to use neurotechnology**. Such protections could include mandating the presence of independent advocates during the consent process, employing age-appropriate and culturally sensitive communication tools, and investing in ethical training for professionals involved and regular audits of consent practices to ensure they are age and context-appropriate.

- .99. Member States should prohibit the misuse of neurotechnology on children such as surveillance, unconsented monitoring, and **forced uses** that may enhance wellness.
- .131. Member States should ensure that informed consent procedures for neurotechnology are comprehensive and transparent, providing detailed information about the purposes, risks, benefits, alternatives, and possible outcomes of the technology. These procedures must emphasize that consent is entirely voluntary and ensure individuals fully understand the implications for their privacy, autonomy, and well-being. Additionally, **individuals must have the clear right to refuse or withdraw from neurotechnology treatment at any time,** ensuring their autonomy and respect for their decision-making capacity is upheld.

Informed Consent/Assent

We applaud the extensive references throughout the draft to consent and, to a lesser extent, assent. We assess that these instances are well positioned in support of the key sections in the draft where they are critical.

Our concern is about the "state of IC practice" and its "readiness" to ensure that consent/assent are effectively able to be secured across the use cases discussed in the draft and beyond. We are reflecting on the current absence of robust consent/assent templates, training, assessment and refinement processes in this regard.

This "readiness" issue represents an important implementation challenge for the recommendations. We believe that the AHEG should consider adding analysis and language which recognizes this gap and which discusses pathways and actors who can address it as a key enabling factor in implementation.

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