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| **Human Rights Council Advisory Committee****Questionnaire on “Neurotechnology and human rights”** |

**Background**

In accordance with Human Rights Council [resolution 51/3](https://undocs.org/A/HRC/RES/51/3), 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]](#footnote-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]](#footnote-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.

**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.

So far Portugal has not taken any action although crimes against the mind, for example, have been discussed in academia as a possible criminalization.

1. Is there any actor in the public or private sector developing this kind of technology in your country? Please provide information, if possible.

Portugal has no prominent actor at an international level, although small companies such as Insignals Neurotech explore the potentiality of neurotechnology, mainly in the medical field. Portugal also has the Sociedade Portuguesa da Neurosciência, which focuses on the bigger field of neuroscience.

1. 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.

As I am developing my master’s thesis (under the European master of human rights EMA) in the correlation of human rights and neurotechnology, developing an HRBA and analysing the necessity of further legislative developments to accommodate this area, I would position myself as highly aware.

*Impact, opportunities and challenges*

1. What human rights will be mostly impacted by the development and use of neurotechnologies? Identify the three rights most impacted and briefly explain why.

The three rights that can be most impacted are; the right to freedom of thought, the right to privacy and the right to health. While the two first rights with negative outcomes if measures are not taken; the third one with a positive impact.

The right to freedom of thought stands for the freedom of one to develop and keep their thoughts without any exterior interference. What neurotechnologies enables is to access and interfere directly with one´s mind, through stimulation of certain areas mapped as related to certain thoughts. This compromises the thinking process and its uniqueness. The DBS devices have been used mainly to help people with depression[[3]](#footnote-3). and some patients relate to feeling disconnected from their own thoughts, affirming things as ‘I do not feel myself anymore’ or ‘I feel like a robot’[[4]](#footnote-4), which suggests that the thoughts were not free anymore but induced by an external device. These technologies can also pose problems of manipulation of the user or neuro-marketing[[5]](#footnote-5) if not properly regulated.

Measures on the limits of such interventions, as, for example, if inducing one´s attention or memory is altering freedom of thought or not needs to be considered. We defend that since these two characteristics are developed externally and accepted to be developed externally, through education or taking daily vitamins, it is still not included on what is considered the freedom of thought.

The right to privacy includes, although requires further development and clarification, mental privacy. Since BCIs need to record and process brain activity to detect what one wants to communicate[[6]](#footnote-6), what is the command to an external device[[7]](#footnote-7), or to understand which part of the brain is to be stimulated[[8]](#footnote-8), it creates a direct connection to the mind, enabling misuses. Brain activity stands for both the thoughts and the thinking process, which allows the understanding of how one thinks. Brain activity does not only enable one to understand thinking processes as to identify one or one´s characteristics, similar to genetic data. Both represent privacy concerns.

There are three types of BCIs regarding the brain activity recorded: active BCIs, which are consciously controlled and independent of external events; reactive BCIs, which arise from the user´s reaction to external stimulation; and the ones using arbitrary activity without voluntary control from the user, outputs to passive BCIs[[9]](#footnote-9). The last category is always a threat to privacy since excludes the possibility of having any type of private sphere.

Lastly, the lack of security can open the possibility of brain hacking[[10]](#footnote-10), which can be seen as connected with the problems of computer hacking but deeply expanded, since a brain has even more private information than a computer. All this calls for strict regulation on the right.

Regarding the right to health, neurotechnologies enable first a more profound knowledge of the brain that permits finally a better understanding of neurologic diseases that until now could not be explained[[11]](#footnote-11). Secondly, it allows its treatment[[12]](#footnote-12).; the treatment of the symptoms, as with DBS for depression[[13]](#footnote-13); or at least to stop the degenerative effects, as within Alzheimer’s. Thirdly, it allows a better integration of people under a medical condition or a disability[[14]](#footnote-14), since BCIs can open a channel of communication directly through brain activity, so people that cannot speak or move may communicate with others; permitting to control an external motor device as a bionic hand, enabling people with paralysis to gain autonomy; and can contribute to detect attention or stimulate it for people with ADHD, contributing to a more equal ground of opportunities. The BCI developed by Magnus Medical[[15]](#footnote-15) or the projects of Neurolink[[16]](#footnote-16) to restore full body functionality are examples of BCI in the service of health. The different scenarios regarding the right to health demands a promotion of states.

1. 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?

The different challenges and risks regarding BCIs in general increase with consumer-orinted neurotechnologies, posing serious problems on equality and the creation of societal pressure to take advantage of neurotechnologies. The risks can be summarised by safety, privacy, algorithmic bias and predictability.

The first point should be raised both regarding the device and its implantation[[17]](#footnote-17). Although magnetic or electrical radiation in contact with the scalp represents a risk, the argument has a special intensity regarding invasive BCIs[[18]](#footnote-18) due to their implantation. Such BCIs cumulate the risks of surgery, possible infections[[19]](#footnote-19) and biocompatibility[[20]](#footnote-20). These points have been raised in FDA´s answer about Neurolink´s brain chip[[21]](#footnote-21).

Even guaranteeing the safety of BCIs to the user´s health, there is a serious threat to privacy protection[[22]](#footnote-22). The BCIs are to be connected with external devices open to suffering from cyber-attacks. This form of attack has been mentioned as brain-hacking[[23]](#footnote-23) and the information collected is as private as one´s thinking. The relevance is even stronger when considering the type of brain information recorded. Passive BCIs that use arbitrary brain activity without voluntary control[[24]](#footnote-24) present a totally uncontrolled threat for the user that possesses no means to protect himself regarding his unconscious brain activity[[25]](#footnote-25). These same attacks, in stimulating BCIs, can program a wrong stimulation with the creation of undesirable and potentially dangerous brain activity, leading even to possible manipulation.

The third group of questions is not a particularity of BCIs, being verified in any human or artificial human decision, although comporting increased importance in such context. The direct connection to the brain that BCIs open requires a special concern about any tendency or discrimination, intentional or unintentional[[26]](#footnote-26). The risk of unintentional bias is also increased by the still-existent lack of knowledge of the brain.

The brain is still an undisclosed organ, as mentioned even by the International Brain Initiative pioneer in this investigational field[[27]](#footnote-27), for any intervention present an unpredicted factor[[28]](#footnote-28). To add, multiple processes depend on AI[[29]](#footnote-29), some even on deep learning[[30]](#footnote-30) that, although being more trustful technologies from day to day, still have a margin of error. The fact that a brain sub-sector is identified by AI as responsible for certain thinking does not prove that *x* comes from that region. Ai relies on the information of which sub-sector of the brain is commonly active when the user thinks about *x*. However, it is possible that the testers always think about *y* when thinking about *x*, and the brain activity that the AI algorithm detects is instead related to *y*.

All these concerns deserve full attention and should be the basis for the improvement and construction of future BCIs, however, they relate to present problems that are expected to be overpassed or dimmed through the development of the field, aligned with the progress in AI and Neuroscience. The evolution of technology demonstrated that technical difficulties tend generally to find an answer. On the other side, fundamental issues are the ones that occupy the centre of the debate, regarding not the state of the art today, but what should be the state of the art tomorrow. Stimulating BCIs are not only able to help in the treatment of neurologic and psychological diseases, as can be a path to augmentative intelligence or post-humanity[[31]](#footnote-31).

Question regarding the human-machine merge are not only the loss of what can be considered an identity but the loss of the perception of what is an identity. There is a self-subjective experience that can be lost without even being understood as such.

The dependency created should also be questioned both through a practical and a theoretical perspective[[32]](#footnote-32). The problem can be raised given the high costs of these devices, the facility to lose the necessary funding and the harmful impact of its post-use. Patients that have been later deprived of a BCI have related difficulties in re-adaptation to life as well as affirm that they have lost a part of themselves[[33]](#footnote-33). The question should also be considered theoretically, assessing the desirability of such dependence.

A last ethical challenge that besides theoretical is also practical is the threat to equality that these devices create[[34]](#footnote-34). The general lack of access, justified by the high cost, creates a strong gap between who has the possibility to acquire and enjoy the benefits from BCIs and those that for lack of resources do not have the opportunity to invest in a better version of themselves. In a world marked by a generalized use of powerful BCIs the freedom not to use one is merely apparent if one wants to guarantee that one has equal opportunities to its pairs[[35]](#footnote-35). Equal opportunities come as demand in contexts such as education or the work market.

1. What groups are more vulnerable or at risk? Please, identify three and explain why.

Although some groups may benefit from neurotechnologies as some people with disabilities or under certain medical conditions; others can be deeply prejudiced.

The main group being prejudiced are people living in poverty. They can be affected by the high costs of neurotechnologies, which will obstacle their consumption. The use of neurotechnologies, mainly augmentative ones implies strong advantages, in education or the labour market, that will be accessible only to a few. On the contrary, to try to keep up with the market such groups will be more vulnerable to accept to participate in tests that do not meet all the safety conditions or that demonstrate to pose risks to health if those are provided in more affordable conditions.

The same disadvantages can be felt by people who even having the necessary money to afford neurotechnologies chose not to do it, as the decision may signify a loss of productivity or value for the labour market.

1. 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?
2. From a human rights perspective, what opportunities could the use of neurotechnologies bring? Can these opportunities be balanced against the identified risks and impact?

BCIs is a scientific progress that has raised high hopes in the therapeutic, medical and research field[[36]](#footnote-36) as a form of guaranteeing health, inclusion and equality.

These devices end up being an asset for the promotion of equality, both of means, being communication a fundamental for better participation in any social context including in a work context; and of results, providing the possibility of an equal and independent enjoyment of life[[37]](#footnote-37). The health conditions, with which one is born or that arbitrarily acquires through life stop having such a predominant role in the personal enjoyment of life.

BCIs also demonstrate to be a valuable instrument in the discovery of the brain and its research[[38]](#footnote-38). BCIs research works as a cycle as is a requirement to develop BCIs but also benefits from the recordings made by BCIs for a deepness of knowledge and the development of new devices. Such research contributes not only as a motor for the strengthening of the realization of the rights previously mentioned as it can provide more insides into the human being and what is to be human[[39]](#footnote-39).

*National framework*

1. 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.
2. Does national legislation on privacy and data protection cover mental privacy[[40]](#footnote-40) and/or personal brain data?[[41]](#footnote-41) Please explain.
3. 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?
4. Is your national institutional framework for human rights well-equipped to address the new challenges posed by neurotechnologies?
5. 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*

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

The Human Rights framework provides already relevant instruments to regulate neurotechnology, such as the right to science and its General Comment 25; the Universal Declaration on Bioethics and Human Rights; the Recommendation on the use of AI; the right to freedom of thought and the right to privacy. However, there is a lack of development and clarity regarding these rights and ethical frameworks. However, there is still a major problem of clarity on how to apply a HRBA to such disruptive technologies, which led a vast number of authors to develop proposals for new rights, the neurorights. These rights represent an undesirable bureaucratization of the system once this already provides adequate rights to address the question.

Additionally, there are questions regarding a person´s identity and how neurotechnologies may impact it that find no answer under the UN´s framework. What is one´s identity, the impact of the mind on one´s identity and how brain activity is part or influences one´s mind[[42]](#footnote-42) need to be addressed to tackle this gap.

1. 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.

The definition of a human rights-based approach by the Human Rights Council could facilitate comprehension and provide guidelines for national regulation. Such regulation should address states’ duties in the tripartite structure, defining the duties to promote neurotechnologies that generate inclusion of marginalized groups or contribute to substantive equality, as BCIs that enable people with paralysis to control devices, as a bionic hand[[43]](#footnote-43), or people that cannot speak to communicate through brain activity[[44]](#footnote-44). On the other hand, define states’ obligations to protect from neurotechnologies that endanger the sense of identity[[45]](#footnote-45), mental privacy[[46]](#footnote-46) and safety, mainly regarding invasive BCI[[47]](#footnote-47).

The right to privacy should be clarified as protecting both indirect access to the mind, as protecting letters or diaries; but also direct one´s as it is possible, or will potentially be possible with BCIs. Right to freedom of thought should also be developed as comprising the right to have free thinking processes and not as the freedom to decide to use BCI´s that endanger the substantive freedom of thought as a unique and personal dimension itself.

Lastly, the importance of ethics should be recognized and understood as insufficient under the current framework. The Universal Declaration of Bioethics provide important principles such as autonomy or consent, however, is insufficient to tackle questions on human identity and what is the ethical limit to resembling a person to a machine. A Declaration on Neuroethics should be adopted by UNESCO and under International Bioethics Committee control and promotion, as the committee with expertise in ethics and the biological field. Neuroethics is not an opposed area of Bioethics but instead, a special area of bioethics that requires specific protection. This proposal is sustained in the importance of brain activity in the concept mind, and the fundamental character of the mind in one´s identity. The importance of protecting the person´s identity led to the Universal Declaration on the Human Genome and Human Rights and to the International Declaration on Human Genetic Data, what justifies the same treatment to brain activity, comprising both the processes and the information, as the processes contain also information of one´s way of thinking. The recognition of brain activity as a special type of personal data supports the promotion of more strict and specific national regulation on the area.

1. 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?

To provide a human rights-based approach the Human Rights Council for its visibility and mandate towards all human rights.

 For a Declaration on Neuroethics, UNESCO and the International Committee on Bioethics, for its expertise in the area and the past successful cases related to the human genome and genetic data.

COMEST even though experienced with science ethics reveals insufficient experience regarding the biological field. The Covenants and respective Committees could be relevant to monitoring the respect for the rights mentioned, however, the fact that neurotechnologies require an interrelated analysis of different human rights, both civil and political as economic, social and cultural, as the fact that general comments on science, freedom of thought and privacy without particularly relevant provisions on neurotechnologies fade away its utility.

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

1. What specific characteristics would you emphasise as unique and distinctive of neurotechnologies?
2. 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.
3. 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?
4. Does your company or organization implement the principles for responsible innovation in neurotechnology?[[48]](#footnote-48) Please elaborate.
5. 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.
6. What national regulation or framework do you consider is needed to avoid a potentially negative human rights impact of neurotechnology?
7. 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)

1. 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).
2. Please describe any measures undertaken aimed at coordinating, collaborating or seeking synergies with the work of other organizations in relation to neurotechnology.
3. 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)

1. 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.
2. 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.
3. What actions could be undertaken by the Coordination Committee of Special Procedures to address any negative human rights impact arising from neurotechnology?
4. 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?
5. 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)

1. 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).
2. 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.
3. 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?
4. 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)

1. 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.
2. 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?
3. 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?

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