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Analysis of the existing European human rights framework concerning the human rights issues raised by neurotechnologies and their applications

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LIST OF ABBREVIATIONS

CFR: EU Charter of Fundamental Rights

CHRB: Council of Europe's Convention on Human Rights and Biomedicine (Oviedo Convention)

ECHR: European Convention on Human Rights

ECtHR: European Court of Human Rights

ICCPR: International Covenant on Civil and Political Rights

ICESCR: International Covenant on Economic, Social and Cultural Rights

UDHR: Universal Declaration of Human Rights

1. Introduction

Neurotechnologies offer unprecedented possibilities for accessing, recording, altering data from the human brain, and even for predicting individuals' behaviour. These devices and procedures can be either non-implantable in a wearable form or implantable via surgery. Brain imaging techniques, various forms of brain-computer interfaces, transcranial and intracranial electrical stimulation, and other related technologies have great potential to improve the well-being of neurological patients by providing new diagnostic, preventive, and therapeutic tools. Besides medical applications, advancements in this field offer new opportunities for self-monitoring mental health and cognitive performance, brain-controlled computer usage, communication, and even entertainment.

However, these same technologies open the door to unparalleled threats to human rights and human dignity that were unthinkable only a few decades ago. As rapid advancements are being made in this area, it is increasingly urgent to consider the adequacy of existing legal frameworks to effectively protect the privacy of people's mental sphere from unsolicited interferences.

In addition to concerns about mental privacy, the possibility of altering neural data through neurotechnologies generates disquiet about the possible emergence of sophisticated forms of mind control and infringements on freedom of thought, self-determination, personal identity, and mental integrity.

Undoubtedly, the human interests that are potentially endangered by neurotechnologies are important enough to deserve protection through human rights norms. It is worth remembering that the brain is the organ most directly linked to our decisions, thoughts, and memories – in essence, to the core of our personality, our *self,* and therefore, to our *dignity* as human beings. It is evident that we are encountering in this field a wide range of unprecedented threats to human personality and dignity that require a strong response from the legal system and, particularly (but not exclusively), from human rights standards.

The present report aims to assess whether the current European human rights framework is well equipped to address these new challenges or if it has some gaps. It intends to serve as a first step toward developing an interpretative guide to adapting European human rights frameworks in order to address these new challenges.

Let us remember that the cornerstone of the European human rights system is the European Convention of Human Rights (hereafter, ECHR or simply "the Convention"). Drafted in the aftermath of the Second World War, the ECHR was adopted in 1950 and entered into force in 1953. It almost exclusively protects civil and political rights, that is, the so-called "first generation rights", which are the rights of liberty that protect individuals against violations by the state, such as the right to life, privacy, fair trial, freedom of thought, of expression, freedom from torture and inhuman and degrading treatment, from discrimination, etc. In contrast, economic, social and cultural are not

addressed by the Convention, and were left to a separate and later document.[1] This focus of the Convention on the rights of liberty is interesting for the purpose of this report because most of the rights that are stake in the context of neurotechnologies are rights of first generation. Thus, there a natural affinity between the philosophy that inspired the ECHR and the rights that are especially impacted by neurotechnological developments.

It is also important to mention that the ECHR has strong enforcement mechanisms and provides for both state and individual applications. According to Articles 33 and 34, any contracting state and any individual, non-governmental organisation and group of individuals may bring an application alleging a breach of the Convention by a state that has ratified it. The system's centerpiece is the European Court of Human Rights (ECtHR), a judicial body responsible for interpreting the Convention and ruling on alleged violations, and whose judgements are binding for states.

The analysis made in this report pays particular attention to the ECHR and the jurisprudence of the ECtHR. In addition, it considers other relevant European legal instruments, notably the Council of Europe's Convention on Human Rights and Biomedicine (hereafter, Oviedo Convention), and the EU Charter of Fundamental Rights (hereafter, CFR).

This report also takes into account the three pillars of the international human rights system: the 1948 Universal Declaration of Human Rights (hereafter, UDHR), and the two 1966 International Covenants on Civil and Political Rights (hereafter, ICCPR), and on Economic, Social and Cultural Rights (hereafter, ICESCR). This analysis also considers the discussions and recommendations made by a group of experts at a round table jointly organised by the Council of Europe and the OECD (Organization for Economic Cooperation and Development) in 2022 (O'Sullivan et al., 2022).

[1] The economic, social and cultural rights are enshrined in the European Social Charter, which was opened for signature in 1961 and became effective four years later. A separate monitoring committee oversees its implementation.

2. Human rights impacted by neurotechnologies

Today, most experts seem to agree that, to a greater or lesser extent, existing human rights need to be reinterpreted or expanded to encompass the emerging issues raised by neurotechnological advances (Ligthart et al, 2023, p. 464-465). Some of those experts even consider that at least some novel human rights must be created to deal with these challenges more effectively (Ienca and Andorno, 2017).

So far, the academic debate on the so-called "neurorights" has been largely focused on determining the "list" of rights to be included in that category, how they should be defined, and whether they are entirely new rights or just extensions of existing rights. In contrast, important questions concerning the effective *implementation* of these rights, and how they should be *balanced* against other human rights and social interests have not been sufficiently addressed in the literature.

Despite academic controversies on how or to what extent existing human rights frameworks must be adapted to offer protection against misuse of neurotechnologies, there is currently a strong consensus on the human values involved in this area and the need to uphold them through human rights norms, as well as civil and criminal legislation. This is visible in the various reports, declarations and recommendations that have been adopted or are being prepared by various international and regional organisations like UNESCO, OECD, the Human Rights Council, and others.[2]

Taking into account these documents and the scholarly work in this area, the rights particularly relevant for dealing with the challenges posed by neurotechnologies appear to be: a) mental privacy, b) cognitive liberty and freedom of thought, c) mental integrity, and d) personal identity.

2.1 Mental privacy

Respect for mental privacy is the right that is most immediately at risk with the increasing access to neural data enabled by neurotechnologies. The notion of mental privacy refers to the idea that people should have control over the access to and use of their neural data by others. It is important to note that such data can provide insights into a person's neurological and psychological health and, to some extent, help infer mental processes and even decipher people's mental states, thoughts, and personal preferences. Moreover, data from the nervous system can be used to make predictions about a person's future cognitive abilities and potential neurological illnesses. This type of data is arguably far more sensitive and intimate than any other biometric or health data. Therefore, it is crucial today to implement appropriate policy measures to safeguard individuals from unauthorized access to their neural data.

[2] See UNESCO IBC, 2021; UNESCO Ad Hoc Expert Group, 2024; UN Human Rights Council Advisory Committee, 2023; OECD, 2019; Council of Europe, 2021; OAS-IJC (2023).

It is noteworthy that neurotechnological tools can collect and store a vast amount and variety of neural data. These data can potentially be accessed by third parties without the individual's consent or with consent that is not entirely free because it is affected by lack of adequate information, coercion or deception. Such data, combined with AI tools, will likely give a variety of actors the ability to make inferences about users of neurotechnologies and unfairly disadvantage some of them, based on inferences about their predispositions to neurological conditions, "prediction" of future behaviour, or, more generally, about their cognitive capacities or mental states, giving rise to the so-called "neurodiscrimination" (Muhl & Andorno, 2023). Among the third parties that could potentially misuse neural data for discriminatory purposes are, for instance, employers interested in monitoring their employees' concentration at work, schools wanting to scan children's brains to check their attention levels, and even authoritarian governments keen on identifying regime opponents.

Hence, to prevent such abuse of something as intimate as people's thoughts, preferences, memories, and mental states in general, the formal recognition of a "right to mental privacy" has been proposed over the past few years (Ienca and Andorno, 2017; Yuste et al., 2017). This right can be seen as an extension of the widely recognised right to privacy but applied to a particularly sensitive type of data: *neural data.*[3]

Certainly, international and European human rights norms already recognise a general right to privacy, including the confidentiality of personal data. The foundational instrument of international human rights law, the UDHR, provides:

> "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks" (Article 12)

This norm is restated in almost the same words in the 1966 International Covenant on Civil and Political Rights (art. 17). For its part, the Universal Declaration on Bioethics and Human Rights adopted by UNESCO in 2005 provides that

> "The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to" (...) (Article 9).

At the European level, the ECHR recognises a right to respect for one's "private and family life, his home and his correspondence" (Art. 8, para 1). According to paragraph 2, this right can be subject to certain restrictions that are "in accordance

[3] "Neural data" have been defined "quantitative data about the structure, activity and function of the nervous system, both the central and the peripheral, of a living organism" (Council of Europe's Consultative Committee of the Convention for the Protection of Individuals with Regard to the Automatic Processing of Personal Data (Convention 108) (2024), para. 1.3). In the present report, the expression "neural data" refers exclusively to data obtained from human subjects.

with the law" and "necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

The Oviedo Convention expressly refers to the right to privacy regarding personal health data when it stipulates that

> "[e]veryone has the right to respect for private life in relation to information about his or her health" (Art. 10, para. 1).

Similarly, the EU Charter of Fundamental Rights, after providing that "[e]veryone has the right to respect for his or her private and family life, home and communication" (Article 7), stipulates that "[e]veryone has the right to the protection of personal data concerning him or her" (Article 8, para. 1). Moreover, "[s]uch data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law" (idem, para. 2).

As can be seen from the above-mentioned norms, the right to privacy is conceived very broadly by international and European human rights law as it covers many heterogeneous elements. This makes it difficult to identify this right's content in very precise terms. It is not by chance that the right to privacy has been described as the "least defined and most unruly of the rights enshrined in the [European] Convention" (Harris et al., 2022, p. 508).

Hence, the key question is: *Do the above-mentioned legal provisions apply to the privacy of the mind and the confidentiality of neural data?* As a matter of fact, in current human rights law, there is no explicit recognition of a right to mental privacy. Therefore, the dilemma is whether we need to expand the interpretation of the right to privacy to better protect our inner sphere. Scholars have discussed this question intensively over the past few years. Many of them agree that some specific provisions regarding mental privacy must be envisaged. Some of them think that just some minor specifications in existing norms would suffice, while others consider that formally recognizing a right to mental privacy would be helpful for its implementation, even if this right is ultimately no more than a specification of the general right to privacy.

Regarding European human rights law, the first interpretative issue is whether Article 8 of the ECHR can be understood in the sense that it also includes a right to mental privacy. Let us remember that the ECtHR has defended the doctrine of the Convention as a "living instrument which ... must be interpreted in the light of present-day conditions" and "in line with social and technological developments" (Tyrer v. UK, 1978, para 31; Harris et al., 2022, p. 508). Based on the Convention's preamble, which refers not only to the "maintenance" but also to the "further realisation" of human rights, the Court has concluded in favour of a *dynamic (or evolutive) interpretation* of the Convention (Sudre et al., 2023, p. 240). This approach is commonly referred to as a *teleological* interpretation (from *telos,* meaning finality). Such an interpretation

considers the "object and purpose" of the Convention, which is the advancement of the "ideals and values of a democratic society" (Preamble).

On the other hand, the Court has made it clear that it is not possible, by means of an “evolutive interpretation,” to derive from the Convention and its Protocols, “a right that was not included therein at the outset” (Johnston and Others v Ireland, 1986, para 53). Thus, it is crucial to draw a line between *judicial interpretation,* which is permissible, and *judicial legislation,* which is not. (Harris et al., p. 8.).

What are the implications of the above analysis? Given the dynamic interpretation of the Convention, supported by the ECtHR’s jurisprudence, it can be claimed that neural data obtained through neurodevices are already protected by the general right to privacy. On the other hand, it must also be acknowledged that such data have a very particular status, as they are closely linked to the very core of personhood. This explains why, in some respects, neural data are unique and not comparable to other categories of personal data (Ienca & Andorno, 2017, p. 14; López-Silva, Wajnerman-Paz & Molnar-Gabor, 2024, p. 9-10). However, in order to proceed to an extensive interpretation of Article 8 of the ECHR, it is not necessary to force the ordinary meaning of words. For example, it is doubtful that the concept of "home" in Article 8 of the Convention would need to be interpreted very broadly in order to consider the brain as the “home of our mind” (G. Malgieri in: O’Sullivan et al., 2022, p. 19).

To solve this issue, it has been suggested that, at the level of secondary legislation of the European Union, neural data could be added to Article 9, para. 1 of the General Data Protection Regulation (GDPR) as a new category of specially protected personal data (Bublitz, 2022; European Parliament’s Scientific Foresight Unit, 2024, para. 6.4. and 9.3). This change could certainly be helpful, even though we must acknowledge the significant challenge and time-consuming process of making amendments to regional or international binding instruments. In addition, the update of data protection laws to include neural data is not incompatible but complementary with the formal recognition of a right to mental privacy at the higher level of human rights frameworks.

It is also important to note that when considering the possibility of extensively interpreting legal norms, it is often overlooked that *courts* are responsible for such a task. Indeed, courts have the specific role of applying and interpreting laws to resolve individual cases when conflicts arise. In doing so, they can in principle interpret normative frameworks extensively to fairly resolve the cases at hand.

Yet, considering the importance of the human rights and freedoms that are potentially impacted by neurotechnologies and the urgency of ensuring their protection, relying solely on eventual court decisions seems inadequate. Legislative action appears necessary to ensure respect for human rights in this context. The recent reports, declarations and recommendations mentioned above agree on this point. Indeed, it is indisputable that having specific legal norms for promoting respect for the mental sphere presents important advantages in terms of clarity, consistency and comprehensiveness:

- Specific legal frameworks may contribute to addressing the unique challenges posed by neurotechnologies in clear and distinct terms and minimise uncertainty for individuals, companies, and governments.
- They can lead to more consistent normative standards within each country and, more broadly, across Europe and avoid solely relying on court rulings that may vary from court to court.
- They would enable a more proactive and comprehensive strategy rather than passively waiting for court decisions, which may take years and are tipically only applicable to individual cases.

2.2 Cognitive liberty and freedom of thought

Cognitive freedom is a basic human entitlement that can be violated by the improper use of neurotechnologies, impacting individuals' ability to make decisions on their own. It is a complex notion that connects very directly with inner freedom and agency. In this report, cognitive liberty is understood in the sense of "mental self-determination", meaning that individuals are entitled to exercise control over their own mental states, which cannot be altered or conditioned by third parties without their consent. This notion embodies the idea that individuals have the right to act autonomously, that is, to make their own choices with the aid of their cognitive capacities and free will.

Cognitive self-determination is crucial in a democratic system, as it is a prerequisite for the exercise of many other fundamental rights and freedoms. Indeed, several human rights rely on personal self-determination for their exercise (political rights, freedom of thought and conscience, freedom of speech, freedom of the press, freedom of association, etc.).

Scholars do not yet agree on the precise meaning and content of cognitive liberty. For instance, according to Bublitz (2013), this liberty encompasses both the right to enhance one's mental state through neurotechnological devices and the right to refuse to do so. However, this broad understanding of cognitive liberty is controversial, not only because it would open the door to massive use of neuroenhancement procedures, but also because it would imply that the state should guarantee access to neuroenhancement devices to any individual who so desires, regardless of any neurological condition. Yet, this consequence would be socially problematic, as it would raise serious questions of justice in society, similar to those of doping in sports. Indeed, those who participate in sporting competitions and take performance-enhancing drugs have an unjustified advantage over those who do not. Similarly, healthy people who enhance their cognitive abilities (for instance, memory) by means of neurodevices would have an unfair advantage over non-enhanced individuals in various areas of social life (for instance, in terms of access to jobs). This inequity would be even more serious in socioeconomic contexts, characterised by major inequalities and as it would generate new forms of marginalisation and social exclusion. Therefore,

it seems more reasonable and prudent to understand cognitive freedom only as a negative right, i.e., the right to reject the coercive use of neuroenhancement devices (Ienca & Andorno, 2017, p. 11; UNESCO IBC, 2021, para. 149-151).

Although mental self-determination can be regarded as the prerequisite for many other rights and freedoms, it is not specifically protected by current international and European human rights law.

Article 1 of both the ICCPR and the ICESCR refers to the right to self-determination when it states that

> "All peoples have the right of self-determination. By virtue of that right, they freely determine their political status and freely pursue their economic, social and cultural development"

Yet, self-determination is conceived by both Covenants as a right of *peoples* rather than of *individuals*. This provision was included in both instruments to uphold the collective right to national self-determination within the context of anticolonial processes from the 1960s. Therefore, it is hardly applicable to the challenges to the mental agency of *individuals* posed by neurotechnologies.

It is also important to mention that a very direct corollary of cognitive liberty is the classic *right to freedom of thought,* which neurotechnological applications can jeopardise in unprecedented ways, as they have the potential to both decode and alter mental states, thoughts, personal preferences, and memories and, therefore, open the door to sophisticated forms of mind control.

References to the freedom of thought (in the sense of the freedom to hold one's own opinions and beliefs) can be found in some of the first human rights declarations, such as the French Declaration of the Rights of Man and Citizen (1789), which provides in Article X:

> "No one should be disturbed for his opinions, even religious ones, as long as the *manifestation* of such opinions does not interfere with the public order established by law." (emphasis added)

For its part, the founding instrument of international human rights law, the 1948 UDHR, also refers to the freedom of thought when it states:

> "Everyone has the right to freedom of thought, conscience and religion; this right includes freedom (...) to *manifest* his religion or belief in teaching, practice, worship and observance" (Art. 18). (emphasis added)

Almost identical terms are used by the 1966 ICCPR (Article 18.1), the ECHR (Article 9.1), and the EU CFR (Article 10.1).

It is interesting to note that all the above-mentioned instruments only refer to the freedom to *manifest* one's thoughts. The problem with this narrow notion is that the challenge posed by neurotechnologies is not the freedom to express one's opinions or beliefs (the *forum externum,* or external dimension of thoughts), but the freedom of

thought in its literal and deepest sense, that is, the freedom to think by oneself and autonomously without being monitored or controlled by others (*forum internum,* or internal dimension).

In this regard, it is noteworthy that the drafters of the UDHR and other foundational human rights instruments did not foresee the tremendous progress in neuroscience and neurotechnology that took place in the following decades. Therefore, historical statements about freedom of thought are not necessarily a reliable guide for analysing this right in a contemporary context (Ligthart et al., 2021). Thus, it is not surprising that the 2021 UN Report on the Freedom of Religion or Belief points out that the scope and content of freedom of thought "remain largely underdeveloped and poorly understood" (Shaheed, 2021, para 4). For this reason, the Rapporteur emphasizes the need for "further clarity on the legal content and scope" of this freedom and encourages the adoption of a General Comment on the freedom of thought to help establish the missing clarity. More specifically, in relation to neurotechnologies, the Rapporteur considers that, according to a broadly shared view among experts, "contemporary legal frameworks are unprepared for emerging predictive and neurotechnologies and their implications for freedom of thought, amongst other rights" (ibid., para 79).

It is true that Article 18, paragraph 2 of the ICCPR could be seen at first glance as a useful tool against unauthorized uses of neurotechnologies, as it states that "(n)o one shall be subject to coercion which would impair his freedom to have or adopt a religion or belief of his choice". However, this provision is too narrowly focused on "religion and beliefs" and does not include other categories of thoughts or personal preferences whose manipulation under coercion would also constitute a serious infringement upon the *internal* dimension of the freedom of thought. In addition, the 1993 UN Human Rights Committee's General Comment on Article 18 expressed the view that the coercion referred to by paragraph 2 only involves the "use of threat of physical force or penal sanctions" (UN Human Rights Committee, 1993). Therefore, it is unclear whether it would also cover the unconsented manipulation of thoughts using neurotechnological means when no such threats are made.

2.3 Mental integrity

While the right to bodily integrity protects against interference with one's body, the right to mental integrity aims to protect against certain forms of interference with one's mind. However, there are differing interpretations regarding the type of interference that would violate mental integrity.

Some scholars have proposed a very broad definition of mental integrity as "the individual mastery of his mental states and his neural data so that, without his consent, no one can read, spread or alter such data in order to condition the individual in any way" (Lavazza, 2018). The problem with this overly broad definition is that it overlaps with mental self-determination and even with mental privacy. Being so general and

unfocused, it becomes useless because of its ubiquitous nature (Blumental-Barby & Ubel, 2024).

This is why it seems preferable to define mental integrity more narrowly so that it has a more specific goal and can be distinguished from other human rights violations in this area. In this regard, it has been proposed that, by analogy with the right to physical integrity, the element of *harm* would be characteristic of the right to mental integrity. While the right to physical integrity protects against harm to the body, the right to mental integrity would protect against harm to the mind (psychological harm by means of neurodevices (Ienca & Andorno, 2017).

Some might argue that this right would be superfluous given that the brain is part of the body, and the body already enjoys the established protection of a right to physical integrity. However, this objection does not consider that the kinds of bodily interference that infringe on the right to physical integrity do not necessarily correspond to the kinds of mental interference that infringe on mental integrity. For instance, non-invasive forms of brain stimulation or brain-computer interfaces (BCIs) may harmfully interfere with brain activity and behaviour, and severely violate one's right to mental integrity. However, they may not violate the right to physical integrity despite having serious impacts on a person's mind (Ligthart et al., 2023). In addition, it should be considered that individuals using invasive neurotechnology, such as Deep Brain Stimulation, could be at risk of having their device hacked by malicious actors, resulting in psychological harm (Ienca and Haselager, 2016; Ienca and Andorno, 2017).

The right to mental integrity has not played a very important role in European human rights law so far, and, as a result, its scope and meaning remain vague (Bublitz, 2013, p. 248; Istace, 2023, p. 226). Certainly, the EU CFR explicitly mentions the right to both physical and mental integrity. Article 3, titled "Right to the integrity of the person", states that "everyone has the right to respect for his or her physical and mental integrity" (para. 1). However, it is primarily understood as a right to mental health. This seems to be the meaning of mental integrity in the Convention on the Rights of Persons with Disabilities (CRPD), which states that: "Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others" (Article 17). Nevertheless, there is a lack of clear definitions or guidelines to interpret Article 3.1 of the CFR, and neither the explanatory reports nor the preparatory works of Article 3 of the CFR offer any guidance (Istace, 2023, p. 223).

For its part, the Oviedo Convention defines the purpose of the instrument itself by appealing to the notion of integrity in Article 1:

> "Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their *integrity* and other rights and fundamental freedoms with regard to the application of biology and medicine" (emphasis added).

However, no explicit reference to *mental* integrity is made in the Convention. The Explanatory Report to the Convention does not specify how the term "integrity" must be understood.

The ECtHR's jurisprudence has referred to the right to mental integrity on some occasions and has associated this notion either with the right to private life enshrined in Article 8 of the ECHR, or with the prohibition of inhuman or degrading treatments, included in Article 3 of the ECHR. The notion of mental integrity was used, for instance, to refer to the psychological harm resulting from the police inaction towards the continuous harassment experienced by a disabled person by other individuals (Dordevic v. Croatia, 2012), the distress suffered by an asylum seeker woman whose small child was detained and deported to her home country (Mayeka and Kaniki Mitunga v. Belgium, 2007), the forced administration of emetics (a medicine that induces vomiting) to an individual to provoke the regurgitation of a bag containing illegal drugs that he had allegedly swallowed (Jalloh v. Germany, 2006), or the threat of being deported to his country of origin, where he could face inhuman or degrading treatment (Bensaid v. United Kingdom, 2001), or the maltreatment, including assault, sleep deprivation and insults inflicted on an individual placed in police custody (Akkoc v. Turkey, 2000).

It is worth noting that in all of the above-mentioned cases and similar cases, psychological harm is somehow the indirect consequence of others' illegitimate behaviour. But the use of neurotechnological devices is different and unique in that psychological harm is not solely caused by another person's abusive behaviour but also (or mainly) the direct result of a technological intervention in the brain (for instance, through the hacking of an implanted neurodevice). Therefore, we are faced with situations that are not entirely comparable.

2.4 Personal identity

Various brain stimulation procedures can (intentionally or unintentionally) alter people's identity or *sense of self.* The term "identity" is here understood as the set of qualities, preferences, beliefs, and other important personality traits that characterize a person. Being so closely related to *who* we are, it can be claimed that those qualities or features cannot be intentionally altered by others without one's consent. As Paul Tiedemann points out, we understand ourselves as personal unities and as subjects and sources of attitudes as long as these attitudes have a minimum level of coherence. This is why a serious lack of coherence makes it impossible to understand oneself (Tiedemann, 2016). Consequently, it seems important to prevent neurotechnologies from being used in ways that could disrupt people's sense of identity, and challenge fundamental assumptions about the nature of the self and personal responsibility (Yuste, Goering, Arcas et al., 2017). Not surprisingly, over the past few years, it has been argued in favour of the formal recognition of a "right to personal identity" or a "right to psychological continuity" (Ienca & Andorno, 2017, p. 20-23; Yuste, Goering,

Arcas, et al., 2017). This proposal has generally received a positive echo from experts (UNESCO, 2021, p. 11-13). Interestingly, a study of the potential gaps in international and regional human rights law regarding neurotechnologies concluded that the least protected “neuroright” is precisely the right to personal identity (Genser, Herrmann and Yuste, 2022, p. 8).

Based on the very broad wording of Article 8 of the ECHR (right to respect for private life), the jurisprudence of the ECtHR has recognised the notion of “personal identity” in cases concerning, for instance, access to information about one’s biological origins (Gaskin v. UK, 1989), the establishment of a legal parent-child relationship between children born from a surrogate mother abroad and their biological father (Mennesson v. France, 2010), the use of a family name (Burghartz v. Switzerland, 1994), the mention of one’s correct ethnicity on the identity card (Ciubotaru v. Romania, 2010), and sexual identity (Goodwin v. UK, 2002).

Explicit references to personal identity are rare and generally vague in international and regional human rights law instruments. For instance, the Convention on the Rights of the Child (1990) includes the “right of the child to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference” (Art. 8). The Convention on the Rights of Persons with Disabilities (2006) refers to the right of children with disabilities “to preserve their identities” (Art. 3.h), and emphasises the importance of preserving the “linguistic identity of the deaf community” (Art. 24.3.b).

At the European level, neither the ECHR nor the CFR mentions a right to personal identity. The Oviedo Convention defines its purpose by reference to the need to “protect the dignity and *identity* of all human beings” (Article 1). However, the Explanatory Report to the Convention does not offer any guidance on the definition of identity. The main concern for mentioning "identity" appears to have been the potential for changes in the human germline and the need to preserve the human identity for future generations (see paragraph 14).

3. Conclusions and recommendations

Neurotechnologies play an important role in improving the well-being of patients with neurological disorders by offering new preventive, diagnostic, and therapeutic tools. These technologies also provide useful devices for mental self-assessment, communication, and many other legitimate purposes.

However, these same tools pose unprecedented threats to human rights and dignity. Notably, they can be used to gain unauthorised access to individuals' mental information as well as to jeopardise freedom of thought, personal identity, and mental integrity and self-determination.

Human rights are called to play a central role in addressing these emerging challenges, as the fundamental human interests at stake in this field are directly related to the very core of human personhood and dignity. It is interesting to mention that protecting the mental sphere through human rights involves, to some extent, revisiting the first generation of human rights (i.e. rights of liberty) and therefore aligns well with the philosophy that inspired the adoption of the ECHR in 1950.

In recent years, various international or regional organisations have proposed regulatory principles for governing neurotechnologies, or are in the process of doing so. These proposals are very encouraging because they show a high degree of consensus on the basic rights and freedoms that are at stake in this area.

So far, much of the academic discussion has revolved around whether the normative principles that have been proposed should lead to the creation of entirely "new" human rights (the so-called "neurorights") or more modestly, to the interpretive expansion of existing human rights to cover the novel issues. As a matter of fact, this debate is more of a theoretical nature and is not very relevant from a practical perspective. Let us not forget that human rights have basically a *practical,* not a *theoretical* purpose; they aim to promote and protect fundamental human basic goods and interests. Therefore, the really key issue is *how to best protect those basic goods and interests that are at risk in this area.* In other words, the crucial questions that still need further discussion among experts and lawmakers are:

a) how those rights (notably, mental privacy, cognitive liberty, mental integrity, and personal identity) can be effectively *protected by the law,* and

b) how they should be *balanced* against other human rights and social interests.

The precedent analysis of international and European human rights law shows that existing normative frameworks are ill-prepared to deal with the emerging issues. Therefore, it is not surprising that most legal experts agree that some adaptations of existing human norms are necessary. Indeed, virtually no one defends the position that there is no need for normative action to prevent the misuse of neurotechnologies and that we should rely solely on court decisions.

It is true that courts could, at least within certain limits, interpret the existing human rights framework extensively to cover the novel issues. However, as mentioned previously, establishing specific legal standards at domestic, regional, and international levels would provide significant advantages in terms of clarity, consistency, and comprehensiveness of the responses to the new challenges.

It is also important to remember that intergovernmental human rights instruments should focus on developing frameworks of general principles. This is because national governments, rather than international organisations, are the primary agents responsible for enforcing human rights. Intergovernmental organisations play a significant, albeit subsidiary, role in establishing commonly shared principles. However, the primary locus for effectively implementing those standards is the domestic level through more detailed norms (notably, civil and criminal law norms). This is clear, for instance, in the Oviedo Convention (see Articles 23 to 25).

What should be the nature of intergovernmental normative frameworks to be adopted at the European level? The logical first step in this process would be the adoption of a soft law instrument, such as a recommendation (see O'Sullivan et al., 2022, p. 28-29). Soft law instruments have the invaluable advantage of allowing a broad and rapid consensus on common standards between governments. This is particularly valuable when dealing with complex or sensitive issues, such as those related to scientific developments. These kinds of instruments are a great asset because they allow countries to gradually become familiar with the commonly agreed standards before having to deal with the adoption of enforceable rules (Andorno, 2013, p. 37-41). This strategy, of course, does not prevent the initiation of the years-long process required for the adoption of a legally binding instrument, such as, for instance, an Additional Protocol on the Oviedo Convention.

In summary, based on the findings presented in this report, the following recommendations can be made:

Recommendation 1: *Updating the European human rights framework and domestic laws to better respond to the specific challenges posed by neurotechnologies*

In the context of the Council of Europe, it is recommended as a short-term measure to adopt a soft law instrument, such as a recommendation.[4] This instrument would provide a framework of principles for specifically addressing the novel challenges to human rights posed by neurotechnologies. That set of common principles should guide European countries in adapting their domestic legislation to the emerging issues in this area. This strategy does not rule out the possibility of starting the process of creating a legally binding document (for instance, an Additional Protocol to the Oviedo

[4] Recommendations are adopted by the Committee of Ministers. See Article 15b of the Statute of the Council of Europe: "In appropriate cases, the conclusions of the Committee may take the form of recommendations to the governments of members, and the Committee may request the governments of members to inform it of the action taken by them with regard to such recommendations".

Convention). In parallel, domestic lawmakers should be encouraged to adapt civil, criminal, labour, and procedural laws to respond satisfactorily to the new challenges.

Recommendation 2: *Requiring free and informed consent for the collection and use of neural data and recognising the sensitive nature of such data*

The collection, storage and use of neural data should only take place with the free and informed consent of the individuals from whom the data are gathered. In addition, enhanced security measures should be taken to preserve the confidentiality of such data and to prevent unauthorised third parties from gaining access to the identity of the data subjects. Given the close connection of neural data to highly personal information (including health information), they should be labelled as “sensitive personal data” and encrypted using the highest quality procedures.

Recommendation 3. *Recognising a right to mental privacy*

Besides adding neural data to the category of sensitive personal information in data protection laws, it would be helpful to recognise a right to mental privacy at the higher level of human rights principles. This recognition would contribute to emphasise that the issue at stake in this area is not just the protection of a specific category of personal data, but rather the preservation of the *self* from illegitimate technological intrusions, given the very close link that exists between mental states and personhood.

Recommendation 4. *Ensuring freedom of self-determination and freedom of thought*

It is crucial to prevent the use of neurotechnologies to intentionally influence or manipulate people's decision-making processes, as this would seriously violate individuals' self-determination and freedom of thought. The ability to make decisions based on one’s own free will and personal preferences is one of the most cherished values in democratic societies and must be preserved at all costs. In other words, human rights frameworks should ensure that individuals maintain the freedom to think and act without being manipulated or conditioned by third parties or the state through the use of neurodevices.

Recommendation 5. *Guaranteeing a right to personal identity*

Legal frameworks should ensure that individuals' personal identity is not intentionally altered by third parties or the state through the use of neurotechnologies. The psychological continuity of individuals deserves to be protected by law, guaranteeing that each person can continue to perceive themselves as the same person over time. In particular, brain stimulation procedures, whether for medical or non-medical

purposes, should be closely monitored to prevent any impact on users' identity without their knowledge and free consent.

Recommendation 6. *Ensuring the right to mental integrity*

Laws should prevent neurotechnologies from being used in ways that harm people's psychological dimension. Although violations of mental integrity may sometimes overlap with the transgression of the previously mentioned rights, the right to mental integrity aims specifically at preventing psychological harm. In this context, civil and criminal laws that address, respectively, compensation for damages and punishment for harmful behaviour are especially relevant. This right holds particular significance due to the potential increase in criminal activity involving the malicious use of neurotechnologies in the upcoming years.

Recommendation 7. *Preventing neurodiscrimination and algorithmic biases*

Legal frameworks, including labour regulations, must clearly state that the information derived from neural data should not be used to determine decisions related to employment and other relevant areas, unless those conditions pose a risk to the safety and health of the individuals themselves or other persons. Laws must also establish that the informed consent given by employees to the use of neurodevices at the workplace is not free if it is obtained by any form of coercion, in particular if it cannot be refused without any detriment. In addition, measures have to be taken to prevent or mitigate algorithmic biases in artificial intelligence-based devices used to process and analyse neural data.

Recommendation 8. *Being cautious in the authorisation of neurotechnologies for enhancement purposes*

The use of neurotechnological or pharmacological cognitive enhancement devices by healthy individuals should be regulated with particular caution. The use of such devices without therapeutic justification could be socially problematic, as it could lead to an unfair advantage for the neuroenhanced individuals over others in various areas of social life, such as access to jobs or in the assessment of school or university performance. In this sense, the emergence of a social gap between people who have decided to increase their cognitive abilities and those who could not or chose not to do so must be prevented.

Recommendation 9. *Establishing mechanisms for the effective protection of rights related to neurotechnologies*

The mere formal recognition of human rights specifically related to neurotechnologies would be useless if it were not accompanied by the establishment of rapid and effective procedural mechanisms for the protection of such rights. It is therefore recommended that states create such remedies, in conformity with Article 13 of the ECHR.[5] In this regard, it has been suggested that, similarly to the *habeas corpus* and *habeas data* remedies that are admitted in certain countries against, respectively, arbitrary arrest and misuse of personal data, an emergency judicial remedy called *habeas mentem* or *habeas cogitationem* (from 'cogitatio,' meaning thought) could be created to enforce the rights related to the protection of the mental sphere (Muñoz and Marinaro, 2024).

Recommendation 10. *Creating specialised agencies to monitor neurotechnologies*

States should establish supervisory and oversight bodies to ensure that the use and application of neurotechnologies comply with human rights standards and minimise risks and negative impacts on individuals' rights. This principle involves the creation of specialised national agencies to monitor all phases of the neurotechnology life cycle, including their commercialisation and use. Additionally, these agencies should promote responsible innovation in neurotechnology and encourage the industry to integrate ethical and legal considerations in the design of their products.

[5] "Everyone whose rights and freedoms as set forth in this Convention are violated shall have an effective remedy before a national authority notwithstanding that the violation has been committed by persons acting in an official capacity."

References

Andorno, R. (2013). *Principles of international biolaw. Seeking common grounds at the intersection of bioethics and human rights.* Brussels: Bruylant.

Blumental-Barby, J. & P. Ubel (2024), Neurorights in question: rethinking the concept of mental integrity, *Journal of Medical Ethics,* 2024 May 15:jme-2023-109683.

Bublitz, J.C. (2013). My mind is mine!? Cognitive liberty as a legal concept, in: E. Hildt and A. Francke (eds.), *Cognitive enhancement*, Springer, chapter 19, p. 233-264.

Bublitz, J. C. (2022). Novel Neurorights: From Nonsense to Substance. *Neuroethics,* 15:7.

Council of Europe (2021). *Common human rights challenges raised by different applications of neurotechnologies in the biomedical field.* Report commissioned to Marcello Ienca by the Committee on Bioethics (DH-BIO) of the Council of Europe. Strasbourg, Council of Europe.

Council of Europe's Consultative Committee of the Convention for the Protection of Individuals with Regard to the Automatic Processing of Personal Data (Convention 108) (2024). *The Privacy and Data Protection Implications of the Use of Neurotechnology and Neural Data from the Perspective of the Convention.* Report by Eduardo Bertoni and Marcello Ienca. https://rm.coe.int/expert-report-neuroscience/1680afd3c8

European Parliament's Scientific Foresight Unit (2024). *The protection of mental privacy in the area of neuroscience. Societal, legal and ethical challenges*. Report prepared by an expert group commissioned by the Panel for the Future of Science and Technology.
https://www.europarl.europa.eu/stoa/en/document/EPRS_STU(2024)757807

Genser, J, Herrmann, S., and Yuste, R. (2022). *International Human Rights Protection Gaps in the Age of Neurotechnology* (report). New York: The Neurorights Foundation.

Harris, D., O'Boyle, M., Bates, E., and Buckley, C. (2022). *Law of the European Convention on Human Rights,* 5th ed., Oxford: Oxford University Press.

Ienca, M. and Haselager, P. (2016). Hacking the Brain: Brain-computer Interfacing Technology and the Ethics of Neurosecurity. *Ethics and Information Technology,* vol. 18, 117-129.

Ienca, M. and Andorno, R. (2017). Towards New Human Rights in the Age of Neuroscience and Neurotechnology. *Life Sciences, Society and Policy* 13(1):5.

Istace, T. (2023). Protecting the mental realm: What does human rights law bring to the table? *Netherlands Quarterly of Human Rights,* 41(4): 214-234.

Ligthart, S., Douglas, T., Bublitz, J.C., Kooijmans, T., and Meynen, G. (2021). Forensic Brain-Reading and Mental Privacy in European Human Rights Law: Foundations and Challenges. *Neuroethics,* 14:191-203.

Ligthart S. et al. (2023). Minding Rights: Mapping Ethical and Legal Foundations of 'Neurorights'. *Cambridge Quarterly of Healthcare Ethics,* 32: 4, pp. 461-481.

López-Silva, P., Wajnerman-Paz, A. & Molnar-Gabor, F. (2024). Neurotechnological Applications and the Protection of Mental Privacy: An Assessment of Risks. *Neuroethics* 17, 31.

Muhl, E. and Andorno, R. (2023). Neurosurveillance in the workplace: do employers have the right to monitor employees' minds? *Frontiers in Human Dynamics,* 5:1245619.

Muñoz, J.M. and Marinaro, J.A. (2024). You shall have the thought": *habeas cogitationem* as a new legal remedy to enforce feedom of thinking and neurorights. *Neuroethics* 17, 18.

OAS-IJC (Organization of American States' Inter-American Juridical Committee) (2023). Inter-American Declaration of Principles Regarding Neuroscience, Neurotechnologies and Human Rights, CJI/RES. 281 (CII-O/23) corr.1. At: https://www.oas.org/en/sla/iajc/docs/CJI-RES_281_CII-O-23_corr1_ENG.pdf

OECD (Organization for Economic Cooperation and Development) (2019). *Recommendation of the Council on Responsible Innovation in Neurotechnology*, OECD/LEGAL/0457. https://www.oecd.org/science/recommendation-on-responsible-innovation-in-neurotechnology.htm

O'Sullivan, S., Chneiweiss, H., Pierucci, A., and Rommelfänger, K. (2022). *Neurotechnologies and human rights framework. Do we need new rights?,* Report to the Council of Europe, Strasbourg.

Shaheed, A. (2021). *Report of the Special Rapporteur on freedom of religion or belief: Freedom of Thought.* A/76/380. United Nations, Geneva. Available at: https://www.ohchr.org/sites/default/files/Documents/Issues/Religion/A_76_380_AUV.docx

Sudre, F., Milano, L., Pastre-Belda, B., Schahmaneche, A. (2023). *Droit européen et international des droits de l'homme,* Paris, PUF.

TechEthos Project (2022), EU Horizon 2020 Programme. *Analysis of international and EU law and policy. Part II: Neurotechnologies.* Draft report available at: https://www.techethos.eu/wp-content/uploads/2022/08/TechEthos_D4.1-Intl-and-EU-legal-analysis_Part-II_Neurotechnologies.pdf

Tiedemann, P. (2016). *Identity and human rights. Considerations on a human right to identity.* Stuttgart: Franz Steiner Verlag.

UNESCO IBC (2021). *Report of the International Bioethics Committee of UNESCO (IBC) on the ethical issues of neurotechnology*. Paris, UNESCO. https://unesdoc.unesco.org/ark:/48223/pf0000378724

UNESCO Ad Hoc Expert Group (2024). *First Draft Recommendation on the Ethics of Neurotechnology,* May 2024. https://www.unesco.org/en/ethics-neurotech/expert-group

UN Human Rights Committee (1993). General Comment n° 22 on Article 18, 48th session. At: https://www.refworld.org/legal/general/hrc/1993/en/13375

UN Human Rights Council Advisory Committee (2023). *Preliminary draft report on the impact, opportunities and challenges of neuro-technology with regard to the promotion and protection of all human rights.* https://www.ohchr.org/en/hr-bodies/hrc/advisory-committee/session30/index

Yuste, R., Goering, S., Arcas, B. et al. (2017). Four ethical priorities for neurotechnologies and AI. *Nature*, 551(7679):159-163.

Yuste, R., Genser, J., Herrmann, S. (2021). It's time for neuro-rights. New human rights for the age of neurotecnology. *Horizons*, n° 18, pp. 154-164. Available at: https://www.cirsd.org/en/horizons/horizons-winter-2021-issue-no-18/its-time-for-neuro--rights