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Charting the International Influence of Neuroright(s) Advocacy: insights from an Epistemic Community Analysis

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EXECUTIVE SUMMARY

The increasing development of neurotechnology is a controversial topic given its potential to monitor and model brain activity. While many see the technology's growth as promising, some groups have raised concerns regarding its impact on humanity. Since 2017, a group of people have proposed the creation of rights to address a "regulatory gap" in this technology and protect autonomous control over cognitive activity. The proposal saw initial success in Latin America, a region that has rarely been a pioneer in digital and human rights development and is currently being discussed in international forums such as the United Nations and UNESCO.

With the above in mind, this research aims to understand the group and analyze its influence in the acknowledgment of new rights within the international community. The research starts with gathering public data, and then identifying and describing the members of the epistemic communities. Finally, these factors are evaluated using a list of indicators proposed by the epistemic community's scholars.

The findings show the existence of a community of practice made up of three epistemic communities led by Marcello Ienca, Rafael Yuste, and Nita Farahany. These communities propose to acknowledge four, five, and one additional right respectively in international instruments. Although these communities are always present in the international debate to raise international awareness, their communities do not comply with all the indicators that show influence. A direct example of this is that their efforts have not been enough to get their proposal adopted.

The findings also show two policy implications that need urgent care. The first one is that the discussion on these rights lacks representation of opposing or different views from scholars and researchers, digital rights associations, companies, and funding organizations. Second, the proposal is based mainly on speculation and not backed by proven data, which creates long-term problems. The study concludes by raising the urgent need to engage additional epistemological communities and other stakeholders in the debate and providing financial support to the creation of such communities, as well as including data to support the discussion. Finally, the study urges companies to transparently communicate about their technological advances and allow for open communication with stakeholders to allow public accountability.

INTRODUCTION

The neurotechnology industry is advancing by leaps and bounds alongside the efforts of international organizations to regulate its impact on humans. According to the UK ICO citing the prediction of the Regulatory Horizons Council, this technology will be worth USD 17.1 billion by 2026. (Australian Human Rights Commission, 2023). Likewise, international organizations are currently working on guidelines and recommendations, the most current case being UNESCO that gathered a group of experts to elaborate Recommendations on the Ethics of Neurotechnology in 2024 and that will be adopted at the 43rd General Conference in November 2025. (UNESCO, n.d.-a)

However, this rapidly advancing discussion is not new. Already a few years ago a group of people started the discussion in Latin America and as a result constitutional amendments, bills, digital bills of rights, and a Supreme Court case emerged. If this happened in Latin America, the question arises as to what can be foreseen for the international arena. To understand this, there is a need to understand and know the actors who are behind this discussion that is impacting everyone.

Thus, this research paper seeks to answer: ***to what extent is this group of people influencing the international forum on the creation of new rights***. In answering this question, two objectives will be achieved. First, to know if there is a group formed or not, and second, if there is, to evaluate the influence that this group has.

CHAPTER I: METHODOLOGY

This is a multidisciplinary qualitative research. The analysis is primarily from International Relations and is influenced by Sociology and Law. It is qualitative research because the subjects of the study are human groups and because it is not possible to find reliable data to quantify the influence of a group on international normative development. Within the evaluation, it was considered whether it would be relevant to quantify. However, there is a problem in identifying the variables: Is participation in a forum more important than participation in a call for comments? Is winning a lawsuit sufficient, even if the judgment is not about the campaign issue? It is difficult to put a numerical value on a situation that is based on diverse activities and human contact. Thus, the analysis of epistemological communities was found as the solution to being able to describe and know a group of people.

Due to the short time to carry out this research, only publicly available sources such as social media posts (X and LinkedIn), websites of organizations, and videos of conferences were used. To evaluate as objectively as possible the author reviewed literature on epistemic communities and participated in a course entitled "Brain and Behaviour: An Introduction". Additionally, Google Trends and Google Books Ngram Viewer was used to analyze the internet presence of specific topics.

Additionally, the literature on epistemic communities was used as a guide to identify epistemic communities and assess their influence. Peter Hass's analysis framework was used to organize the information found in publicly available sources. Moreover, the work of Mai'a K. Davis Cross, which compiled a series of indicators proposed by other scholars, was the basis for the list of indicators of influence used in this paper. The series of indicators was enhanced by incorporating the work of Emanuel Adles' and Michael Faubert on the potential of creating agents and giving them agency.

CHAPTER II: CONCEPTUAL FRAMEWORK

1. Neurotechnology

To understand how neurotechnology works[1], the first thing to understand is how the brain works. The brain is 80% cortex and is divided into four lobes, each of which processes certain types of information. For example, the frontal lobe processes thought, organization, short-term memory, movement. The temporal lobes in turn process information about sensory input. Depending on the action humans are performing, a part of our cortex is activated. This activation means that neurons are communicating and exchanging neurotransmitters. Thanks to this, human beings can perform various actions. Now, the brain can suffer injuries such as tumors, wounds, but it can also suffer Aphasia which is when it is not possible to connect a word with an idea or apraxia when movements and thought are not connected. In order to study what happens, there are currently several techniques to understand the functioning of the brain, an example of this is the electroencephalogram (EEG), which measures the electrical activity in the brain through metal discs placed throughout the skull.

[1] The information provided in this part comes from the class "Brain and behavior: an introduction" taught by Dr Anna Scarnà.

Given this, neurotechnologies are those responsible for understanding, monitoring, and modeling the activity of the human brain. One type of neurotechnology is the Brain Computer Interface (BCI), which is a device that allows direct communication between the brain and an external device. This device records the electrical activity generated by neurons, using for example EEG technology or Functional magnetic resonance imaging (FMRI) which measures blood flow in the brain when there is brain activity. The BCI then transmits the recording to another device for further study or applied use such as writing on a screen. Both BCIs that are implanted inside the skull and those that are not.

It should be noted that the development of this technology is not new and its research has been mostly in the clinical field. (Magubane, 2023) Currently, BCIs record medical information, not about thoughts, intentions, or emotional states. (Magubane, 2023) Likewise, there are research projects that are trying to find patterns and predict thoughts using artificial intelligence. This is the case of the project of Jerry Tang, Amanda LeBeL, Shailee Jain, and Alezander G. Huth scientists at the University of Texas. (Tang et al., 2023)

This technological advance has raised some concerns. In its clinical use, one of the most worrisome issues in the use of BCI is to collect the user's consent since sometimes the brain damage he/she has will not legally allow it. On the other hand, in their non-clinical use where these technologies are used to help the person sleep better or concentrate, the concern is about safety. Currently, the Food and Drug Administration is the main public agency responsible for ensuring the safety of these devices. (U.S. Food & Drug Administration, 2021)

2. Epistemic Communities and Communities of Practice

According to Hass "an epistemic community is a network of professionals with recognized expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area" (1992, p.3). These communities achieve power because they have control over knowledge, and information (Hass, 1992, p. 2). In that sense, these communities are born in a combination of situations of lack of certainty, interpretation and institutionalization (Hass, 1992, p.3). In those situations, decision makers do not have the capacity to understand a complex issue and do not have the time to develop such understanding. Thus, these communities come to provide certainty and reduce complexity on a particular issue.

For Hass, the criteria for identifying an epistemic community are that the network of professionals shares common principles, beliefs, common notions of validation, and a "policy enterprise" (1992, p.3). On the other hand, for Maiá K. Davis Cross an epistemic community has a "common culture, selection of new members and their further professional development and personal meetings" (Machoň et al., 2018, p5).

It should be clarified that the ethical standards of these communities are not necessarily tied to their professional codes. An epistemic community's ethical standards arise from its principled approach to the issue at hand, rather than from a professional code. It should be further clarified that while these communities provide clarity and certainty on complex issues, this does not mean that what they proclaim is true all the time. What encourages the study of these communities is the political influence they have (Hass, 1992, p. 23). It should also be made clear that these communities do not have to be large to achieve the desired influence; what matters in such influence are the ideas plus the influence (Hass p.27 - 28). Therefore, the impact of these communities is conditioned: "the range of impact that we might expect of epistemic and epistemic-like communities remains conditioned and bounded by international and national structural realities." (Hass, 1992, p. 7).

Communities of practice, on the other hand, are a group of people who are doing the same thing but from different boundaries "consist of people informally as well as contextually bound by a shared interest in learning and applying a common practice." (Adler & Faubert, 2022, p. 53). The idea of focusing on practice lies in the idea that "knowing requires active participation in social communities and knowledge is not a product but is bound with action" (Adler & Faubert, 2022, p. 48). Thus, it can be concluded as Adler points out that one type of community of practice is the epistemic community (Adler & Faubert, 2022, p. 74).

CHAPTER III: FINDINGS

1. Understanding the Epistemic Communities

Analyzing publicly available information and using the concepts of communities of practice and epistemic communities, this research finds a community of practice that warns of the need to recognize new rights to defend against the loss of autonomous control over cognitive activity. In that sense, this research details how this community of practice is subdivided into three epistemic communities.

1.1. The community members

There are three groups of epistemic communities. Each community is in one way or another led by a person. In the following section, this paper provides the profile of the leaders and other people who belong to this epistemic community.

1.1.1. Community 4 neuro-rights

This community was born from the work of Marcello Ienca and Roberto Andorno in early 2017. They postulate for the first time the creation of new rights from the analysis of the risks of neurotechnology on the cognitive freedom of the human being.

Marcello Ienca

He is an Italian academic, who obtained his PhD summa cum laude from the University of Basel in 2018 in biomedical ethics. He is currently a tenured Associate Professor of AI Ethics and Neuroscience at the TUM School of Medicine, and also Associate Director of the TUM Institute for the History and Ethics of Medicine (TUM School of Medicine and Health, n.d.). In addition, he is Head of Neuroethics for the International Brain Initiative and a member of the Organization for Economic Cooperation and Development (OECD) Neurotechnology Network. He has also been appointed as an expert to the Ad Hoc Committee on Artificial Intelligence of the Council of Europe, the Bioethics Committee, and the United Nations Human Rights Council (UNHRC).

Ienca started writing about privacy and ethics related to neurotechnology in 2015. Initially, his concerns are on the side of crimes that can be realized by accessing BCI-generated information. On April 26, 2017 while doing his PhD at the University of Basel, he published with Roberto Andorno the paper "Towards new human rights in the age of neuroscience and neurotechnology." (Ienca & Andorno, 2017) Additionally, he often serves as an expert commissioner or speaker for organizations such as the OECD, the Council of Europe, the United Nations, and the European Union Parliament (AI for Good, n.d.). Over the years Ienca has published several books, reports and scientific articles. According to Google Trends in a search since January 1, 2017, interest in Marcello Ienca is mostly in Switzerland, Italy, Germany, and to a lesser extent in the United States.

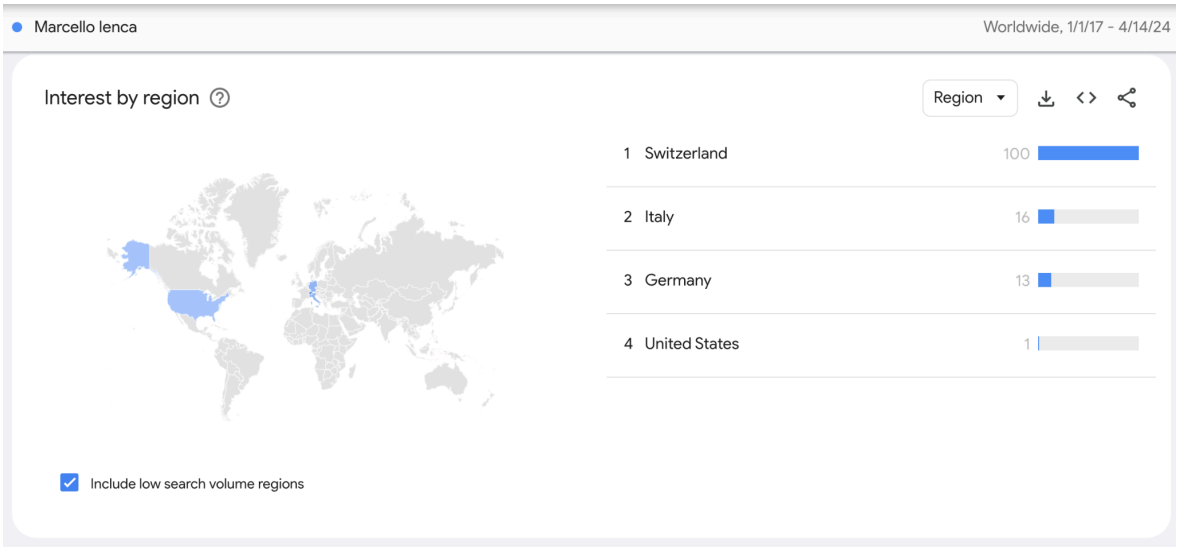

Figure 1. Google Trends result for Marcello Ienca

Roberto Andorno

He is an Argentinean doctor in law who serves as 'Privatdozent' of biomedical law and bioethics at the Faculty of Law, and Research Associate and Coordinator of the PhD Program Biomedical Ethics and Law (Medical Track) at the Institute of Biomedical Ethics and History of Medicine of the University of Zurich. He is co-author of "Towards new human rights in the age of neuroscience and neurotechnology" which he wrote when he was already a professor at the University of Zurich. In addition, he was a member of the International Bioethics Committee of UNESCO between 1998 and 2005. (Institute of Biomedical Ethics and History of Medicine, n.d.) He is a frequent participant in various international events. As it can be seen in the image below, Andorno is searched in Switzerland, Finland, and Latin American countries including his native Argentina. Here Bahamas comes out because Google Trends assigns the weight of searches depending on the size of total searches in the country.

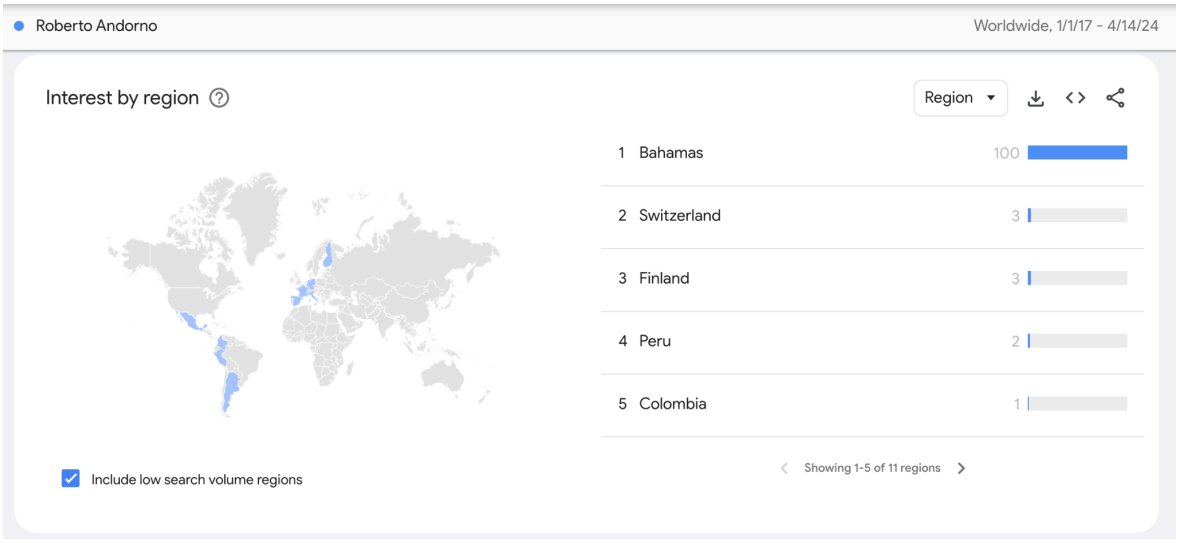

Figure 2. Google Trends result for Roberto Andorno

1.1.2. The Morningside Group - Neurorights Foundation

In May 2017, researchers and scientists representing national brain initiatives that are part of the International Brain Initiative participated in a workshop organized at Columbia University to discuss the ethics of neurotechnologies and machine learning under the auspices of the US National Science Foundation, which used to partially fund the meetings of the International Brain Initiative (Dare, 2023) (Yuste & Goering, 2021) (International Brain Initiative, n.d.). (Dare, 2023) (Yuste & Goering, 2021) (International Brain Initiative, n.d.) This workshop gave rise to the idea of creating the Morningside Group, a network of neuroscientists, technologists, clinicians, ethicists and machine learning engineers from various national brain projects and academic institutions. A few months later, in November of the same year, Rafael Yuste, Sara Goering, Blaise Agüera y Arcas, Guoqiang Bi, Jose M Carmena, Adrian Carter, Joseph J Fins, Phoebe Friesen, Jack Gallant, Jane E Huggins, Judy Illes, Philipp Kellmeyer, Eran Klein, Adam Marblestone, Christine Mitchell, Erik Parens, Michelle Pham, Alan Rubel, Norihiro Sadato, Laura Specker Sullivan, Mina Teicher, David Wasserman, Anna Wexler, Meredith Whittaker, Jonathan Wolpaw published the paper "Four ethical priorities for neurotechnologies and AI". Within this group, the most influential person is Rafael Yuste who is considered the leader of the MorningsideGroup. (Giving to Columbia, n.d.)

Rafael Yuste

He is a Spanish-American professor of Biological Sciences at Columbia University. He is also the director of Neuro Technology Center which was born in 2014 as a response to the US government's "Brain Initiative" where he researches on "optical methods for neuroscience". (Columbia University, n.d.) As part of his research work he has managed to patent his technical advances; two of them are currently commercially licensed. (Columbia University Data Science Institute, n.d.) On the other hand, Yuste is also co-director of the Kavli Institute for Brain Science at the University of columbia and funded by the Kavli Foundation, the same that in 2017 partially funded the annual meetings of the International Brain Initiative. (International Brain Initiative, n.d.)

In 2017 Yuste participates in the workshop as one of the representatives of the Brain Research Through Advancing Innovative Neurotechnologies ("The BRAIN initiative") created in the Obama administration for "the inner workings of the human mind and to improve how we treat, prevent, and cure disorders of the brain." (Dare, 2023) (The Brain Initiative Alliance, n.d.) This public-private initiative had its first meeting on ethics and neurotechnology at the third "BRAIN initiative investigators meeting "in December 2016. There Yuste participated in the neuroethics panel (National Institutes of Health, 2017) that was charged with defining neuroethics and its implications.

Yuste also created the "Neurorights Initiative" which was initially funded by Columbia University to serve as an "advocacy" arm. This initiative later morphed into the Neurorights Foundation which received a 2022 funding of 250,000 from the Alfred P. Sloan Foundation. (Alfred P. Sloan Foundation, n.d.). The work of this foundation took off in January 2018 when Yuste participated in Chile's annual Congress of the Future, a government-funded event that seeks to bring together the scientific community. (The Neurorights Foundation, n.d.-a) It is at this congress where he met Chilean authorities including Guido Girardi, former senator and founder of that congress (LinkedIn, n.d.). Yuste participated in three congresses where he was able to warn about the risks of neurotechnology (República de Chile, 2021).

Since that time his publications and participation in events have included aspects of neurorights. As can be seen in the figure below, thanks to his work in Chile, his popularity grew in Latin America. Thus, Google Trends shows that since January 2017 her name is mostly searched in Spain, Chile, Honduras, Bolivia, and Peru. This coincides with his participation in events and citations that other academics make of his work in those countries.

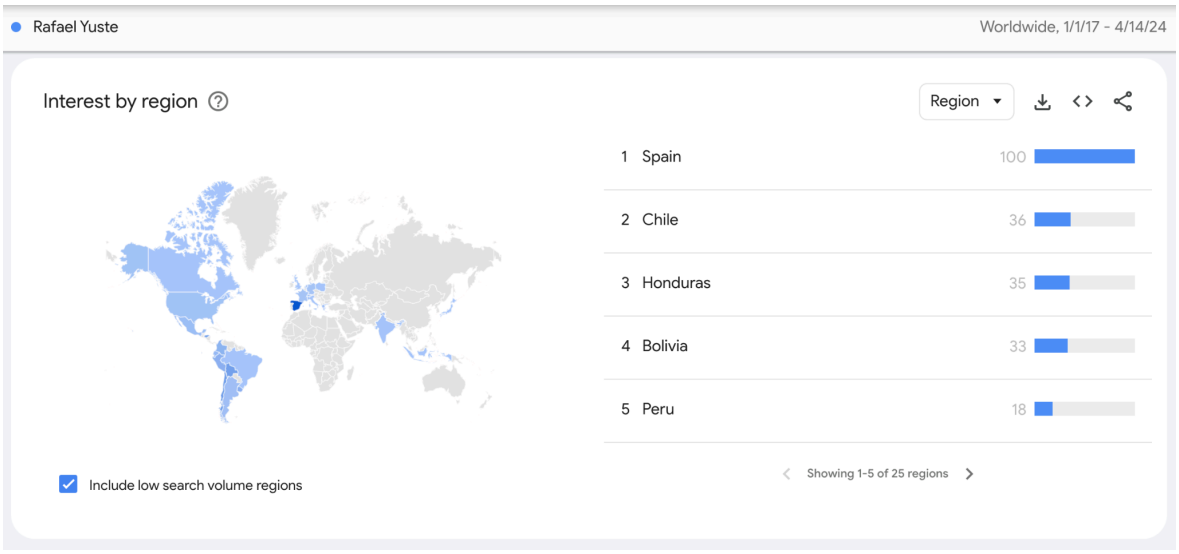

Figure 3. Google Trends result for Rafael Yuste

1.1.3. Comunidad Cognitive Liberty 2.0

As mentioned above and as will be seen in the following section, the concept of "Cognitive Liberty" is not new. However, the "approach" from the perspective of the risks caused by neurotechnology generates this new community led by Nita Farahany.

Nita Farahany

She is an Iranian American scholar who received her PhD in Philosophy from Duke University. She is currently the Robinson O. Everett Distinguished at Duke Universit,y and Founding Director of Duke Science & Society, the Faculty Chair of the Duke MA in Bioethics & Science Policy, and principal investigator of SLAP Lab. Additionally, she is a member of the Global Future Council on the Metaverse and Expert Network for the World Economic Forum. (Nita Farahany, n.d.) She also serves on scientific and ethics advisory boards for corporations. (Nita Farahany, n.d.) In the past, she was an ELSI (ethical, legal, social implications) advisor to the BRAIN Initiative. In 2010 President Obama appointed her to the Presidential Commission for the Study of Bioethical Issues and she was there for seven years.

Starting in 2012 she began to outline academic interest in cognitive freedom with a paper called "Incriminating Thoughts" where she evaluated the importance of

protecting innocent or incriminating thoughts from the right not to self-incriminate (Farahany, 2012). In 2018 this interest turned towards the commercial use of neurotechnology, after participating in the Summit of the Wharton Neuroscience Initiative at the University of Pennsylvania, when she heard about the advances of the technology from Josh Duyan of the company CTRL-Labs. (Farahany, 2021) From that perspective of the risks at work, he then went on to review the risks of neurotechnology in other fields. In 2023 she published the book "The Battle for Your Brain: Defending Your Right to Think Freely in the Age of Neurotechnology (Nita Farahany, n.d.-b). Where he cemented his work on cognitive freedom. In it he uses his experience as a person who has personally experimented with various techniques and technologies that affect the brain.

Farahany is a very active scholar on social networks, constantly participates in national and international events, has given TED talks, and is interviewed on podcasts and radio. This is reflected in Farahany's popularity since January 1, 2017. There is great interest in her in Denmark, the United States, Canada, Australia, and the United Kingdom.

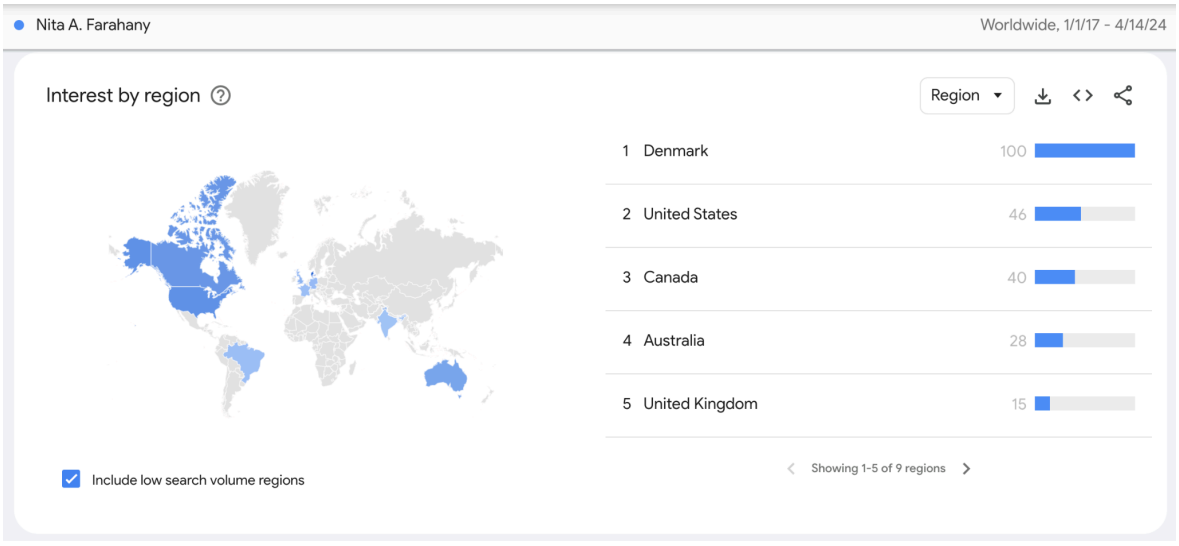

Figure 4. Google Trends result for Nita Farahany

A last point to understand this group of members is to see comparatively the interest that exists worldwide in them. Using the Google Trends tool shows the following for the period from January 1, 2017 to April 14, 2024:

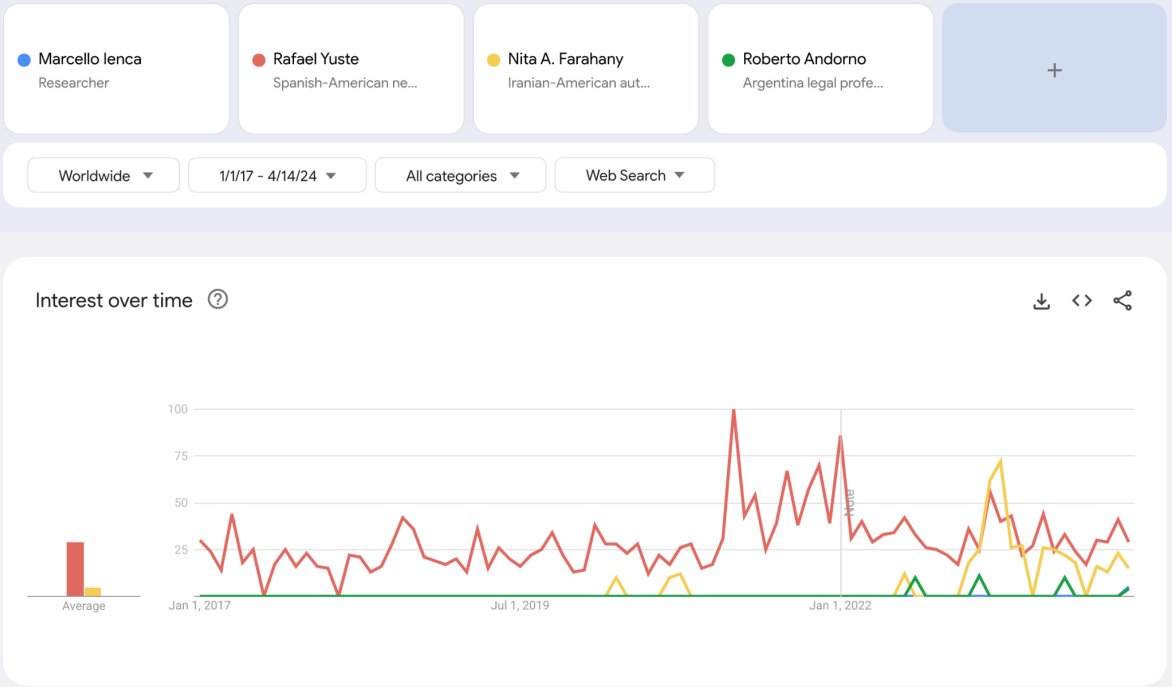

Figure 5. Google Trends comparative result for Marcelo Ienca, Roberto Andorno, Rafael Yuste and Nita Farahany

As can be seen, of these four people, Rafael Yuste is the one who has maintained international popularity over the years. The highest peaks are in 2021, the year in which the constitutional amendment is approved in Chile, being April and September as the key moments of approval of the Senate and Chamber of Deputies respectively.

We also see an exponential growth of searches on Farahany from February 2023, which coincides with the launching of his book in March. On the other hand, both Ienca and Andorno are diluted before the other two individuals.

1.2. The community beliefs and proposals

1.2.1. Community 4 neuro-rights

This community was born from the article: "Towards new human rights in the era of neuroscience and neurotechnology" which proposes for the first time a "neuro-oriented human rights framework" in which the following rights are included: Cognitive freedom, mental privacy, mental integrity and the right to psychological continuity (Ienca & Andorno, 2017). This is because for the authors "neurotechnology remains largely a terra incognita for human rights law. However,

the implications that neuroscience and neurotechnology pose for the inherent characteristics of human beings demand a rapid response." and adaptive human rights law". (Ienca & Andorno, 2017) To legitimize their recommendation, the authors use as an example the work that was done to achieve protection of the human genome through the Universal Declaration on the Human Genome and Human Rights.

In that sense, this community accepts the creation of new rights and the adaptation of old rights. He is also aware of the risk of "inflation of rights" and points out that the proposal does not attempt to contribute to this since it would meet the criteria proposed by Philip Alston to know what qualifies as a "human right."

The work builds on previous work by Richard Glen Boire and Wyre Sententia of the Center for Cognitive Liberty & Ethics. There is a particular work from 2003 that catches the attention of the authors entitled Mind Matters published in the Journal of Cognitive Liberties of the same center. In it, the author makes an explicit call for the first time about the effect of drugs on thinking and how the government can force people to take certain medications in specific situations. The author notes: "It is time to develop a jurisprudence on the mind; one that takes into account the latest knowledge about the brain, the advanced powers of psychopharmacology, and that places them within our country's tradition of embracing individual freedom, self-determination, and cognitive freedom is the human right that most needs immediate elaboration and defense." (Dubois et al., 2003, pp. 9, 10) According to the authors, the laws of that time do not have an explicit recognition of a right. basic to mental sovereignty.

It is worth mentioning that since 1999 and with the Center for Cognitive Liberty & Ethics, the couple Richard Glen Boire and Wyre Sententia have created an epistemic community around promoting cognitive freedom. This was a response to the United States Government's actions that forced some prisoners to take specific medications that could alter their cognition. Unfortunately, the work of this non-profit organization has not been active since 2020. (University Writing Program, s.f.). For them, Cognitive Freedom is the right to control one's mind: the basic building block of personal freedom. In the last decade, this concept became a slogan of support for various struggles for civil rights: among others, demands against non-voluntary interference and forced psychiatry or for the decriminalization of psychoactive substances. (Sommaggio et al., 2017, p.28)

Finally, another previous work that follows the same line as Glen and Sententia is that of Jan-Christoph Bublitz called "My Mind Is Mine!? Cognitive freedom as a legal concept" and published in 2013. Bublitz argues that the law must recognize cognitive freedom or mental self-determination. He also carries out an analysis of German law and finds gaps in the current laws which do not cover the peculiarities of mind interventions. (Bublitz, 2013, p.249)

1.2.2. The Morningside Group - Neurorights Foundation

This community is based on the article "Four ethical priorities for neurotechnologies and AI" (Yuste et al., 2017). The four concerns they detail are "privacy and consent", "agency and identity", "augmentation", "bias" and they explicitly point out that "agency and identity" should be protected as basic rights and that this can be possible with the creation of a convention that defines prohibited actions of neurotechnology and artificial intelligence. The authors of this paper cite as precedent the 2010 International Convention for the Protection of All Persons from Enforced Disappearance. It is from the four concerns that the five rights that Yuste, together with the NeuroRights Foundation and others, promote are born. These rights are mental privacy, personal identity, "free will", "fair access to mental augmentation", and "protection from bias". (The Neurorights Foundation, n.d.-b)

The article also makes some necessary clarifications. He points out that at that time the BCI technology was mainly focused on therapeutic issues and that the concerns they had were part of hypothetical situations that could occur. He explicitly notes that it could take years before the BCI is used daily. The authors take ethics and not human rights as their starting point. In that sense, they explicitly state: "We believe that existing ethics guidelines are insufficient for this realm." (Yuste et al., 2017)

Additionally, the authors clarify that their concerns could vary depending on the needs of different nations and people. For this reason, they indicate that governments must create spaces to mediate an open debate that involves various actors to determine how the proposal they have can be transformed into public policy, laws, or regulations.

On the other hand, these authors also predict that "For neurotechnologies to take off in general consumer markets, the devices would have to be non-invasive, of

minimal risk, and require much less expense to deploy than current neurosurgical procedures." (Yuste et al., 2017)

1.2.3. Cognitive Liberty 2.0

Although this proposal is not new, advocacy on "cognitive liberty" is taking place based on Nita A. Farahany's book titled "The Battle for Your Brain: Defending Your Right to Think Freely in the Age of Neurotechnology." (Nita Farahany, n.d.-b) Her approach is that it is okay to adopt emerging neurotechnologies but only when the concept of freedom can be updated to maximize the risks of doing so.

She further notes that public understanding and dialogue are important. She also uses the phrase "our brains are increasingly the final frontier for privacy. I worry about our laws' ability to keep up with technological change." to denote the urgency of the request. Likewise, as in the two previous cases, a gap is indicated. In this case, the void is normative and the United States Constitution is taken as a reference.

In this way, the book proposes to establish the right to cognitive freedom to protect freedom of thought and rumination, mental privacy, and self-determination over brains and mental experiences. Cognitive freedom then is a set of rights that according to the author should be recognized as part of the Universal Declaration of Human Rights. It should be noted that according to Farahany, her proposal is not about neurorights but about "cognitive freedom" that encompasses existing human rights. She expressly points out that she disagrees with the "neurorights" approach. (Farahany, 2023a)

It is necessary to remember that the proposal of these communities is not entirely revolutionary. It should be noted that there are previous works on some of the proposed rights. As it can be seen in this Google Books Ngram viewer with data from the middle of the previous century, the terms "cognitive liberty", "mental privacy", and "mental integrity", which are widely used in these communities, have been mentioned in publications. previous. It is possible, as in the case of "cognitive liberty", that the approach from which the concept is proposed has changed over time, which does not mean that the concept itself has changed. Something similar would happen with "mental integrity" and "mental privacy".

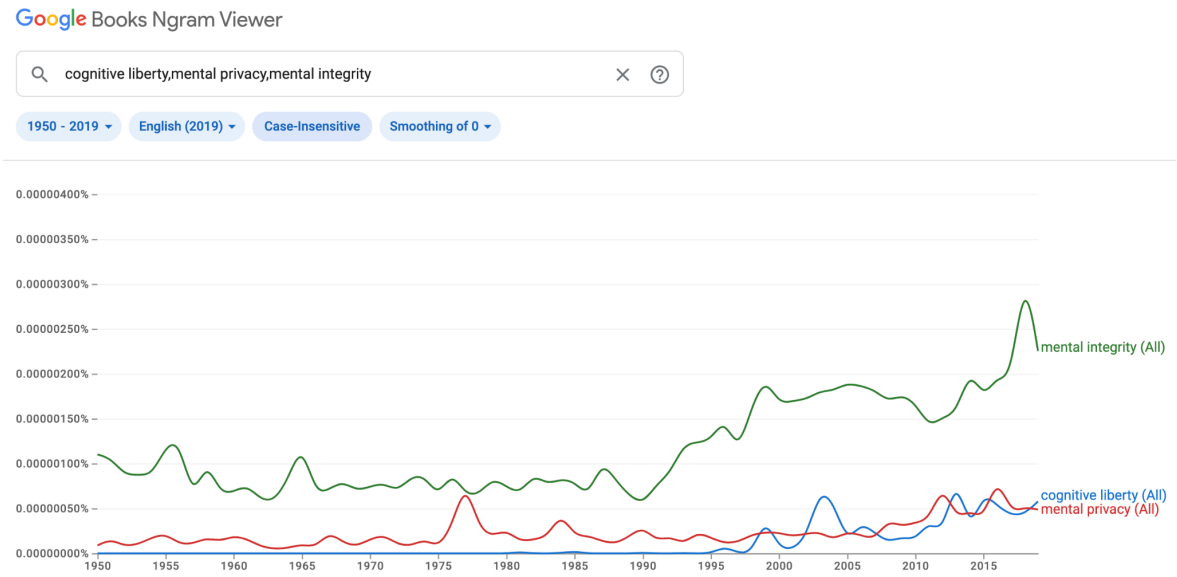

Figure 6. Google Books Ngram Viewer comparative results for "cognitive liberty", "mental privacy", and "mental integrity".

1.3. Their activities and outcomes

In this segment, the paper is going to show the most important activities that these communities are carrying out. These communities have managed to introduce their proposals into the debate. However, the response of the decision-making authorities is not uniform. At the local level, they have achieved binding regulatory and public policy changes that use the same language that these communities propose. However, internationally, the response has been mixed. In the international forum, international organizations are proposing their solutions to the supposed problem of loss of control over cognition. Additionally, it is necessary to mention that no data shows the coordinated activity of these three communities; they act independently but towards the same objective.

1.3.1. Local work

The three communities do local work in different areas. They are usually invited to speak at public events organized by universities (Canal del Congreso México, 2024) (Ienca, 2024) or by authorities and to belong to academic groups. (The Kavli Foundation, n.d.) (International Neuroethics Society, n.d.) (The Hydrid Minds Project, n.d.) Likewise, they are a source of inspiration for new professorships at universities and are constantly interviewed by the press. Within the three communities, the one led by Yuste, through work with the Neuro Rights

Foundation, has developed more local work, the most successful case being the constitutional modification and litigation in the Supreme Court in Chile. Additionally, this Foundation together with other local organizations and strategic partners have worked in Uruguay, Brazil, Mexico, Spain, and the United States. Below the legislative and judicial achievements are shown because they are the ones that generate a concrete and real precedent for international advocacy:

In Chile, the work of the Neurorights Foundation was carried out in conjunction with former senator Guido Girardi and the Kamanu Foundation. This group managed to have Law 21383 approved and published on October 25, 2021, which adds a final paragraph to article N 19.1 of the Chilean Constitution:

"Scientific and technological development will be at the service of people and will be carried out with respect for life and physical and mental integrity. The law will regulate the requirements, conditions and restrictions for its use in people, and must especially protect the ***activity brain****, as well as the information coming from it;"*. (Ministerio de Ciencia, Tecnología, Conocimiento e Innovación, 2021)

Additionally, in Chile, they managed to present in the Chilean Parliament a bill on neurorights and mental integrity, and the development of research and neurotechnologies. This bill defines the following:

"D) ***Neurorights: New human rights*** *that protect the privacy and mental and psychological integrity, both conscious and unconscious, of people from the abusive use of neurotechnologies.*" (Diario Constitucional, 2020)

On September 12, 2023, the Supreme Court of Chile ruled in favor of Girardi against the Emotiv company. Girardi filed a protection appeal arguing that the company stored and commercialized his brain data without his consent, violating his rights to privacy and mental integrity. The Supreme Court ruled against Emotiv, pointing out that it had violated health laws that would allow it to operate in Chile. Because Emotiv was sanctioned, this ruling was presented by the first judicial precedent on a neurorights case. (Asher-Schapiro & Baptista, 2023)

Thanks to all these changes, Yuste has earned a place and legitimacy in Chile that has allowed him to have a meeting with Gabriel Boric, the president of Chile with whom he had a meeting in January 2024 (Yuste, 2024a)

In Spain, in July 2021, the Neurorights Foundation achieved that the Charter of Digital Rights contains a section called "Digital rights in the use of neurotechnologies" which included:

1. The conditions, limits and guarantees of implementation and use of neurotechnologies in people may be regulated by law with the purpose of:
*a) Guarantee each person's control over their own **identity**.*
*b) Guarantee individual **self-determination**, sovereignty and freedom in decision-making.*
c) Ensure the confidentiality and security of the data obtained or related to your brain processes and full control and disposition over them.
d) Regulate the use of human-machine interfaces that may affect physical or mental integrity.
*e) Ensure that decisions and processes based on neurotechnologies are not conditioned by the provision of incomplete, unwanted, unknown or **biased data**, programs or information.*
2. To guarantee the dignity of the person, equality and non-discrimination, and in accordance where appropriate with international treaties and conventions, the law may regulate those assumptions and conditions of use of neurotechnologies that, beyond their application therapeutic, aimed at cognitive increase or the stimulation or enhancement of people's abilities.

Likewise, at a declarative level, the Valencia Culture Council could present the Valencia Declaration on the incorporation of neurorights in the International Declaration of Human Rights on February 24, 2023. It not only cites Yuste and the Neurorights Foundation but also copies the five neurorights exactly using the same language that the Neurorights Foundation proposes on its website. (The Neurorights Foundation, n.d.-b)

*1. **Mental Privacy**: "Any NeuroData obtained from measuring neural activity should be kept private. If it is stored, there must be the right to have it deleted at the request of the subject. The sale, commercial transfer and use of neural data must be strictly regulated."*
*2. **Personal identity**: "Boundaries must be developed to prohibit technology disrupt one's sense of self. "When neurotechnology connects people with digital networks, it could blur the line between a person's consciousness and external technological inputs."*
*3. **Free will**: "People must have ultimate control over their own decision-making, without unknown manipulation by external neurotechnologies."*

*4. **Fair Access to Mental Augmentation**: "Guidelines should be established both internationally and nationally that regulate the use of mental enhancement neurotechnologies. These guidelines must be based on the principle of justice and guarantee equal access."*
*5. **Protection against bias**: "Countermeasures to combat bias should be the norm for algorithms in neurotechnology. Algorithm design should include input from user groups to fundamentally address bias."* (Valencian Council of Culture, 2023)

On the other hand, in Mexico, a bill was also introduced on August 1, 2023, to add the following wording to Article 40 to the political constitution of Mexico:

*"Every person has the right to full and integral individual identity, as well as well as physical and mental integrity as conditions of his freedom. The state will guarantee respect for the **privacy and mental integrity** of people. No authority or individual may, through the use of any technological mechanism, modify, reduce or affect said integrity and **identity**."* (Hernández Pérez, 2023)

While this legislative proposal was in process, in November 2023 this group achieved the publication of the Charter of Personal Rights in the Digital Environment: Good Practices, which contains a chapter on neurorights. This chapter lists the five rights: to the preservation of personal identity, to the privacy of neural data, to non-interference in freedom of decision, to equity in the improvement of brain capacity, and to protection against bias and discrimination. These are the same rights advocated by the Neurorights Foundation. (Institute for Transparency, Access to Public Information, Protection of Personal Data and Accountability of Mexico City, 2022)

In Brazil, on the other hand, this foundation achieved, in January 2024 that the state of Rio Grande do Sul modify article 235 of the constitution to include that *"every individual possesses the **right to mental integrity**, as an inalienable protection against manipulation resulting from advances in neuroscience and neurotechnology"*. (Juvenal Alves Costa Advocacy Desk, 2024)

Additionally, the Neurorights Foundation also managed to get Senator Randolfe Rodriguez to present the bill to amend Article 5 of the Brazilian Constitution to include guarantees on mental protection and algorithmic transparency. In particular, it is proposed to add the following: *"Scientific and technological development will ensure **mental integrity** and algorithmic transparency, in the*

terms of the law." (Senado Federal Gabinete do Senador Randolfe Rodrigues, 2023)

In the United States, there have also been advances in which Yuste has been involved. In Colorado, Cathy Kipp, Kevin Priola, Matt Soper and Mark Baisley, with the support of Yuste, managed to present the bill HB24-1058 (General Assembly of the State of Colorado, 2024) that expands the definition of "sensitive data" of the Colorado Privacy Act to include "biological data" and "neural data" as follows:

(2.5) "biological data" means data generated by the technological processing, measurement, or analysis of an individual's biological, genetic, biochemical, physiological, or neural properties, compositions, or activities or of an individual's body or bodily functions, which data is used or intended to be used, singly or in combination with other personal data, for identification purposes. ***"biological data" includes neural data.***
(16.7) "neural data" means information that is generated by the measurement of the activity of an individual's central or peripheral nervous systems and that can be processed by or with the assistance of a device.

This bill was just passed unanimously in the Colorado Senate on March 29, 2024, and is up to the Governor to sign.(Pauzauskie, 2024).

On the other hand, in Uruguay, Deputy Rodrigo Goñi is promoting a bill on the regulation of neurorights, which is applauded by Rafael Yuste on social networks (Yuste, 2024b) (Yuste, 2024c). The press reports that Goñi expected to present the project in March 2024. (Ámbito, 2024)

1.3.2. International and regional work and responses from international organizations

At the international level, these communities have also been very present at events, writing reports, and sending contributions. Next, the paper will present the activities in international and regional forums and the response from these spaces.

OECD: Responsible innovation recommendations

The OECD is one of the first international organizations that is interested in the subject. Starting in 2015, its Working Party on Biotechnology, Nanotechnology and Converging Technologies worked on the “Neurotechnology and Society” project (The Organization for Economic Co-operation and Development, 2019) which

resulted in the adoption of the "OECD Recommendation on Responsible Innovation in Neurotechnology" on December 11, 2019. (The Organization for Economic Co-operation and Development, 2019) This document includes some language belonging to the community promoting "Cognitive Liberty." As a definition, it is explicitly mentioned: "*Cognitive liberty: the right to mental self-determination*." This concept is then used in the first recommendation on responsible innovation in neurotechnology saying "*1. d. Avoid harm, and show due regard for human rights and societal values, especially privacy,* ***cognitive liberty****, and autonomy of individuals.*" However, this document chose to employ a personal data approach to recommend actions to safeguard brain data and other information obtained through neurotechnology without the need to create new rights. Additionally, the document also recommends prioritizing security, inclusivity in neurotechnology, scientific collaboration, social deliberation, enabling supervisory capabilities, promoting a culture of trust, and monitoring the use of neurotechnology.

Later on May 19 and 20, 2021, the OECD organized the event "Neurotechnology in and for society: Deliberation, stewardship and trust" to discuss the implementation of the recommendations. Ienca participated in this event as moderator and presenter. Among the other participants, there are authorities, researchers from universities, and research centers. There is no evidence of participation as a speaker by other stakeholders (The Organization for Economic Co-operation and Development, 2021). Later on November 9, 2021, the OECD co-organized an event with the Council of Europe where Ienca, Farahny, and Yuste were speakers. At this event, the question about the inclusion of neurorights was deepened. It is unknown if there will be changes or updates to the recommendations made in 2019.

<u>UNESCO: ethical recommendations</u>

UNESCO is currently the body working on a regulatory response to the potential risks of neurotechnology. In July 2019, the International Bioethics Committee of UNESCO decided to begin reflections on ethical issues in neurotechnology as a result, in 2021 they published a report titled "Ethical Issues of Neurotechnology" that includes Ienca's definition of neurorights. (UNESCO, 2022, para n. 17)

This report presents five principles: cerebral/mental integrity and human dignity, personal identity and psychological continuity, autonomy, and mental privacy. Additionally, the report lists a series of human rights that would be challenged by

neurotechnology. For the IBC, the idea of neurorights "embraces certain human rights that are already recognized in national laws, international law and international human rights instruments." (UNESCO, 2022, paras 183 and 185) Therefore, the report recommends that "UNESCO could advise a multidisciplinary group of experts to develop a policy-oriented governance model, to monitor progress in the field, and to examine whether the issues raised are effectively covered by the existing legal frameworks. This governance model would build on the existing human rights architecture and incorporate the relevant principles identified in this report, paving the way towards the eventual elaboration of a new normative instrument on neurorights." (UNESCO, 2022, para 187) The 2021 report is then shared with the Executive Office of the United Nations General Secretariat in two "interdisciplinary expert consultation meetings" in 2021 and 2022, (UNESCO, 2023a, para 20)

One year later, on April 6, 2023, UNESCO published the Preliminary study on the technical and legal aspects relating to the desirability of a standard-setting instrument on the ethics of neurotechnology. (UNESCO, 2023a) This document mentions the debate on neurorights; It is expressly commented that there are concerns and challenges about the definition and implementation of said rights and that the proposal of "neurorights" is still at a conceptual level. However, for the authors, both those in favor and against neuro rights point out that there is "urgent need for having a global ethical framework providing guidance for national policies and regulations to safeguard the rights and freedoms of citizens, individuals and communities from the risks associated with neurotechnology." (UNESCO, 2023a, para. 14) This, added to international advances, makes an ethical response more necessary.

In this way, in May 2023, the Executive Council of UNESCO requested the preparation of a study for the development of a new normative instrument on the ethics of neurotechnology (UNESCO, 2023c, p.15). Months later, on 13 July 2023, UNESCO held The International Conference on Ethics of Neurotechnology. Ienca, Yuste, and Farahany were invited to this event along with other researchers, authorities, and scholars. In the event program, only the participation of a civil society organization dedicated to medical neurology and two people representing the corporate and funding sectors are observed. (UNESCO, 2023d)

According to UNESCO, the main message from the speakers was to support the development of "a global normative instrument and ethical framework similar to UNESCO's Recommendation on the Ethics of Artificial Intelligence." To support

this idea, the event's website shows quotes from Yuste and Farahany that follow that line, emphasizing "lack of protection" and "it needs strong normative framework" respectively. (UNESCO, 2023d)

Also in 2023, Andorno participated in the production of an article and was commissioned for a report. The first is titled "Why human rights are crucial in responding to the challenges posed by neurotechnologies" (2023) and the other is titled "Neurotechnologies and human rights in Latin America and the Caribbean: Challenges and public policy proposals" (2023b) In the latter the author provides a proposal of principles and emphasizes the important transcendental role that UNESCO has, being the entity called to bring together actors and draft a normative proposal, and that said effort would be compatible with other regional efforts. However, it should be noted that the author specifies that the ultimate responsibility falls on the States which have the power to develop binding rules. (UNESCO, 2023, pp. 32, 33)

Currently, UNESCO is working on Recommendations on the Ethics of Neurotechnology, for which it formed a group of twenty-four high-level experts that includes Farahany, Ienca, and Andorno. This group is preparing a draft at the end of April 2024, which will be subject to public consultation and adjustments. The probable date of a final draft is September 2024, after which it will be submitted to intergovernmental consultation. The objective, which had already been set in May 2023, is to present a final text at the 43rd session of the General Conference in November 2025. (UNESCO, n.d.-b)

United Nation Human Rights Council: soft law principles

In 2021, the "Common Agenda" report of the Secretary General of the United Nations mentions neurotechnology as an issue that requires an evaluation of human rights to prevent any type of harm. (United Nations, 2021)

Thus, in October 2022, through resolution Resolution A/HRC/51/L.3, the Human Rights Council asked its Advisory Committee to produce a report on the impact, opportunities, and challenges of neurotechnology on human rights. (United Nations, 2022) For this purpose, it was asked to gather opinions from various interested parties, expressly pointing out civil society, the private sector, the technical community, among others. (United Nations, 2022, para 2) However, after the call for contributions was launched, only some country delegations, medical civil society organizations, and the Neurorights Foundation participated. Likewise,

among the academics, the names of Ienca and Farahany can be found. Along with other scholars from the neurological space and some from law. In that sense, there is a great absence of corporations and traditional civil society groups and digital rights. Months after that consultation, Yuste, Ienca and Andorno participated in a meeting at the Human Rights Council Advisory Committee to comment on the first draft. (United Nations Human Rights Council, 2023)

Currently, there is a final version of the draft of the report presented at the 31st meeting of the Human Rights Council Advisory Committee (2024). This draft recognizes the merit of the "neurorights" initiative because it puts the impacts of neurotechnology on human rights in the spotlight (2024, para. 89). However, it considers, as did the 2021 UNESCO report, that the concerns fall within the scope of existing human rights. (Human Rights Council Advisory Committee, 2024, parr 88) Therefore, it suggests that these rights could be better "shaped" (Human Rights Council Advisory Committee, 2024, parr 89) In that sense, it suggests that "The approval of a soft-law document to protect the human brain and mind could be seen as the corollary of all this process" (Human Rights Council Advisory Committee, 2024, para 89), which would be in the form of a principle or standards. This new instrument would also only have to deal with "mental integrity", "mental privacy" and "mental freedom". This gives some idea about what the Human Rights Council's position would be.

Moreover, it is worth mentioning that other bodies within the United Nations have begun to have discussions about neurotechnology and its legal and ethical consequences. In May 2023, the United Nations Institute for Disarmament Research organized a webinar on this topic in which Ienca participated. (UNIDIR, 2023) Later in November 2023, Yuste would be doing the same at the 78th session of the United Nations Committee against Torture (2023).

The Organization of American States - principles based on data protection

The Organization of American States is the first regional organization that addressed the discussion on rights and neurotechnology. This is not surprising given the progress on this issue in the region. In this way, on August 4, 2021, the Inter-American Juridical Committee, which is a consultative body of the Organization of American States (OAS), approved a document titled “Declaration on neuroscience, neurotechnologies and human rights: New legal challenges for Americas.” (2021) This document was prepared after a consultation with experts including Rafael Yuste. (The Inter-American Juridical Committee, 2023, p.5) Two

years later in 2023 this same committee approved the “Declaration of Inter-American Principles on Neurosciences, Neurotechnologies and Human Rights”[2]. (The Inter-American Juridical Committee, 2023) The document presents a list of ten principles based on recognized human rights and opts for an approach to personal data by placing "*Neural data as sensitive personal data*" in principle 3. Subsequently, on January 25, 2024, the document was endorsed by the ambassadors of several countries and Yuste was present at that meeting (Yuste, 2024d).

Latin American Parliament

The Latin American and Caribbean Parliament (Parlatino) brings together representatives of 23 parliaments in the region and its most important function is to promulgate model laws. In that sense, on May 19 and 20, 2023, the Neurorights Models Law for Latin America and the Caribbean was promulgated. (Parlamento Latinoamericano y Caribeño (2023) This is the only norm at the regional level that manages to adopt the idea of these epistemic communities, especially the one led by Yuste. Thus, it defines **neurorights as the "*new international legal framework of human rights*** *(...)*" (2023, p.15). Therefore, it suggests the legislation of the following rights: mental privacy, identity and autonomy personal, free will and self-determination, equitable access to cognitive augmentation, protection from algorithmic biases, among others. Additionally, this model law creates a competent authority to oversee neurorights.

European Union - nascent stage

Both the Council of the European Union and the European Parliament have been having discussions on neurotechnology. The Spanish presidency has pushed the issue in the Council of the European Union. Together with the European Policy Center, he held an event on September 29, 2023 titled "Neurorights? Protecting fundamental rights in the era of neurotechnology" where for the first time a person representing Article 19, a civil organization with a long history defending human rights in digital issues, participated. However, this person clarified that he was participating in a personal capacity (European Policy Centre, 2023).

[2] The Ibero-American Data Protection Network, which brings together twenty personal data and transparency authorities from Latin America, the Caribbean and Spain among members and observers, approved the Declaration on Neurodata that resolves to adhere to the work of the Inter-American Legal Committee of the OAS. (2023)

On October 24, 2023, the Council of Europe promulgated the "León Declaration on European neurotechnology: a human focused and rights' oriented approach". (Spanish Presidency Council of the European Union, 2023) This document indicates that the European Union is in an incipient phase and recognizes that there is development of these technologies in Europe, which must be carried out respecting human rights. Therefore, it asks that the European Commission evaluate the need to create standards for neurotechnologies used in the defense of human rights.

On the other hand, the European Parliament held an event on November 16, 2023, titled "Neurotechnology and neurorights - Privacy's last frontier", in which Ienca participated as a keynote speaker. Along with him, other professors and authorities presented. Once again other actors from other stakeholders were absent. (European Parliament, 2023)

Council of Europe - still in progress

The Council of Europe, on the other hand, has not made much progress regarding its position on neurotechnologies. The Council of Europe commissioned a report from Ienca entitled "Common Human Rights Challenges raised by different applications of neurotechnologies in the biomedical field" which was published in October 2021.

Subsequently, as mentioned above, the Council of Europe co-organized an event together with the OECD on November 9, 2021 entitled "Neurotechnologies and Human Rights Framework: Do We Need New Rights?". In this event, Ienca, Farahany, and Yuste participated as panelists. (Council of Europe, n.d.) As has happened in other events on neurotechnology and rights, the panelists are mostly academics, scientists, and authorities. There was no presence of civil society or companies.

2. Outside the community's activities

Outside of this community of practice, the issue of the impacts of neurotechnology has different responses depending on the stakeholder. On the one hand, some other scholars and scientists who have a different interpretation regarding what should be done, being in some cases quite critical of the proposal of the community of practice. On the other hand, civil society groups, companies, and

funders are largely absent from this discussion. These stakeholders are not actively working on this issue either.

2.1. Other scholars

The community of practice proposal has generated reactions from the academic and scientific community. However, it is not possible to distinguish a group of people who are completely against the community of practice, nor who propose a specific solution, or take a particular position. Each person has a different reading.

In this way, some of these positions are:

- the concern can be resolved by applying the International Covenant on civil and political rights, (Bertoni, 2024)
- the neurorights proposal does not take into account the context and responds to a hype, (Fernow, 2023)
- the solution is different in each country like in the United Kingdom where there is relevant legislation, (Alegre, 2023)
- it is a topic that is still in development, (López-Silva & Madrid, 2021)
- the constitution of Chile already protected chileans, (Pontificia Universidad Católica de Chile, 2021)
- rights must be focused on actionable and justiciable rights, (Kellmeyer, 2022)
- it would be better if the right to freedom of thought evolved, (Hertz, 2023)
- It is wrong to think that thinking only occurs in the brain, (Zaror Miralles et al. 2021)
- the problem is about procedural guarantees of old rights, (González Álvarez, 2021)
- the speed with which legislation is intended can be problematic, (Bornón et al., 2023, pg. 257)
- these proposals might interfere with the ability to actually treat patients. (LaCasse, 2023)

2.2. Civil society groups work

Civil society groups, foundations, non-profit organizations, and grassroots activists are largely absent in this debate. No public activity has been found on this topic from more traditional organizations such as Amnesty International or Human Rights Watch nor from those specialized in human rights in digital issues such as Access Now, Article 19, APC, EDRI, ACLU, EFF, R3D, Coalição Direitos na Rede,

among others. There was no participation either from their fronts or in the national and international debates except two cases.

Digital Rights, a civil society organization based in Chile and with a long history of defending rights in the digital sphere in Latin America, was the only organization that spoke out against Yuste's proposal. They published a blogspot on April 29, 2021, where they noted the following:

> *"Rafael Yuste proposes that the protection of "neurorights" should be at the level of human rights. This statement should raise skepticism regarding Yuste's understanding of the problem at the rights level and how to address it, since it shows ignorance regarding the developments around the concepts of autonomy, human dignity and self-determination, which have forged the center of the universal system of human rights".* (Derechos Digitales, 2021)

On the other hand, Mark Dempsey, Senior Advocacy Officer at Article 19, was a panelist at the Neurorights? event. Protecting fundamental rights in the era of neurotechnology that mentioned earlier and commented "I am here today I might add in more personal capacity I think **like many Civil Society Organization we haven't reached a position on neuro technologies** and it is clear from the mood in the room that we are at the beginning of the conversation". (European Policy Centre, 2023, 38:57:00). This shows that this stakeholder could be absent because it still sees the issue in its infancy.

2.3. Companies and Funders priorities

As for companies and funders, there is no greater involvement in discussions about the impacts of neurotechnologies. The websites and social networks of the following companies: Emotiv, Wenco, Synchron, StimScience (Somnesleep), Pradromics, Blackrock Neurotech, Neuralink, Neurable, Cognixion, Open BCI, Galea, Midlift, Muse, Mendi, Focus calm, and Neurosity show information about the new products they are launching and most of them include a website or/ and a service privacy policy adapted to the countries they operate. Kernel has a section on how they comply with the General Data Protection Regulation. Galea, Mendi and Focus Calm do not have a privacy policy. Only Sens.ai is governed by a list of privacy principles, however, these principles are not related to the issues that the community of practice works on. (Sens.ai, n.d.)

Therefore, from what was reviewed only Ryota Kanai, Founder & CEO, Araya and Amy Kruse, General Partner & Chief Investment Officer (Satori Neuro), Satori Capital as speakers at the UNESCO event commented on the following without going into many details. Kanai noted: "If we want to make neurotechnology available in the market (consumer products) **we need to build trust from the public**." For his part, Kruse said that "people are uninformed or sensationalized)." and that "Ethical conversations do not magically pop up. Ethical considerations crystallize when you add the patient considerations. **When it stays abstract it gets off the rails**." (UNESCO, 2023b 5:19:15)

3. Communities influence in the international forum

In this segment, the paper shows through an analysis of indicators that the community of practice has not been entirely influential. Although they managed to introduce the debate as seen above, not all the conditions exist for them to be completely influential. An example of this is that they have not achieved international approval of a treaty that recognizes and guarantees the new rights that they propose.

3.1. Analysis

Below the analysis of the impact of the community of practice in the international forum uses the framework proposed by Mai'a K. Davis Cross. (2013, p. 144) A final component has been added to this framework, coming from the work of Emanuel Adler and Michael Faubert. (2022) Therefore, if the community of practice meets all the indicators then it is considered to be an influential community.

3.1.1. Scope conditions

A community can be influential if certain conditions exist about the scope of the topic. For instance, if the issue is complex or new, or if decision-makers are unhappy with public policies and current problems. In the case of this community of practice, the topic of the impacts of neurotechnology is new. Although techniques such as EEG or BCI have been used medically for several years, commercial use is recent. On this side, it can be concluded that the community of practice has fertile ground to work on. However, even though the community of practice narrative uses "loss aversion" as a central component, decision-makers are not at all worried or afraid. As could be seen in the activities they are carrying out, the response at the international level is varied, which denotes diverse

approaches to this issue. In that sense, **in the case of communities of practice, the conditions are not entirely favorable.**

3.1.2. Political opportunity structure

Another point to evaluate is whether community members have access to important decision-makers since this demonstrates soft power. Likewise, this opportunity works more in their favor if they can anticipate the preferences and actions of other actors. Regarding the first, it has been shown that the three Ienca leaders, Yuste and Farahany have access and direct links with decision-makers. The most emblematic case is that of Yuste, who has managed to position himself as an opinion leader in Latin America and especially Chile, where he has managed to have an audience with the president. Furthermore, Yuste's contacts who belong to his community are usually authorities. Clearly, this facilitates the introduction of the debate and also gives it important international political weight. On the other hand, although leaders and their networks are well-connected actors, there is no public information to know if they manage to anticipate the preferences and actions of other actors. Therefore, it is concluded that **the political opportunity is in favor of the community of practice.**

3.1.3. Phase in the policy process

A topic that serves to analyze the influence of these communities is to review the phase in which the public policy process is located. It is advisable to evaluate whether the communities influence in the terms of the initial debate. Likewise, it is analyzed whether these communities know how to deal with the decision-making phases. In the case of the community of practice, it is quite evident that they have managed to start the debate on their terms and know how to navigate between the decision-making phases since they are always present at every step. So much so that the final version of the draft report presented at the 31st meeting of the Human Rights Council Advisory Committee recognizes this work. However, what is not being achieved is that the outcome is the same as what they propose. Although it is not an issue that the authors evaluate, it is pertinent to mention it since it is a central part of the advocacy of epistemic communities. Consequently, at this point, **the community of practice knew how to position its topic and manage the bureaucracy.**

3.1.4. Coalition building

Another important indicator to analyze influence is to check if the networks that compete with the community are not as cohesive or sure of their objectives.

Likewise, it is reviewed whether the community has a high level of status and professional standards. As discussed above, these communities do not have another rival community. There are only people who individually have diverse and contrary opinions. On the other hand, there is not enough data to evaluate how these communities are organized internally; However, it is true that whenever there is an event, members of the communities will always be present, either organizing or exhibiting. Along these lines, it can be stated that **there are factors that denote a certain creation of a coalition that has no rival.**

3.1.5. Policy field coherence

The influence of these communities can also be examined by seeing whether their postulates are based on quantitative data and not qualitative ones and whether the postulate is compatible with existing norms. In this case, critics of these communities point out that work is being done based on "hype" or that the information is not correct regarding the formation of thought. Likewise, at the moment this paper is being written, there is no case of obvious harm to human beings due to the use of neurotechnology in the terms that the communities propose. Even in the case litigated in Chile, the Supreme Court did not rule on whether or not there was damage to the Constitutional rights but rather preferred to evaluate whether Emotiv complied with the health standards in the country. Additionally, the proposal of these communities presupposes that there is a regulatory gap that must be filled. This can be understood as that there is compatibility between your proposal and existing standards. However, the reality is that there are different legal frameworks for the development of human rights which mean that in some jurisdictions there is a greater guarantee than in others. For example, some authors mention that both Chile and the United Kingdom had such guarantees, which does not happen with the United States, which has no regulation on the matter. Therefore, **the proposal of these communities is not based on concrete data nor is it consistent with existing standards.**

3.1.6. The coalition construct agents who have agency (from Adler & Faubert, 2022)

Finally, a point to evaluate is also whether the community builds agents and gives them agency to develop. Within the communities that were studied, the community led by Yuste is where the creation of agents can be seen the most. Through charismatic domination in the style of Weber (2014), Yuste begins to have key people in each country where she works with her organization NeuroRights Foundation. He manages to be seen as an exemplary person and therefore

attracts attention and legitimacy from other people. Some of these people become key people and through the work they do they also begin to be seen as exemplary people, thus gaining legitimacy. Just check the social networks of the Foundation and Yuste to see the support given to these new agents. Therefore, **at least one epistemic community has managed to create agents and give them agency.**

CHAPTER VI: DISCUSSION

This research has found three epistemic communities led by Ienca, Yuste, and Farahany which constitute a community of practice. This community proposes the creation of right(s) as a normative solution to the loss of autonomous control of cognitive activity. This community of practice has managed to introduce the debate on this proposal at a local and an international level. However, this community does not meet all the necessary conditions to conclude that they are influencing international decisions. For example, it has been possible to show that the actors in international and regional forums have opted, except one, for other alternatives that are not necessarily normative.

These findings are important because they make visible two public policy problems that currently directly affect the response that international organizations are having. Therefore, it is suggested that these points be addressed before these international organizations continue making decisions. The problems are:

1. There is an urgent need to involve other stakeholders in the international debate to make it multistakeholder

Although there were various activities to socialize and seek input on the impact of neurotechnologies on human rights, participation has been only from these communities, authorities, and other scholars and scientists. The major absentees in the debates, and those that tend to participate are civil society and the private sector. Especially in Chile, it was seen that there was no participation of citizens or community members who will exercise these new rights, being the most absent voices (Karen S. Rommelfanger et al., 2022). It is also highlighted that there is not yet a deep and broad academic debate that is of great relevance to a new topic. (Asis, R. de., 2022) Ienca himself points out that “its relative sporadic nature in the academic literature raises a risk of semantic-normative ambiguity and conceptual confusion.” (Ienca, 2021, p. 6)

Having a broad debate where different stakeholders participate at the same level is essential and is a pillar of Internet governance. (World Summit on the Information Society, 2005, para. 34) As the philosopher Pierre Teilhars de Chardin said, who divides three stages of evolution, we are currently in the stage of thought, having passed the geological and biological stages. It is in this stage where a universal consciousness is created and occurs through the exercise of the intelligence and knowledge of all of humanity. (Patino, 2019, p.45) Creating this knowledge must involve the contribution of several fronts. Giving authority to a group of elite specialists can further limit access to power by the public. (Hass, 1992, p. 24)

Therefore, on this point it is preliminarily advisable that international organizations actively include other epistemic communities and other stakeholders; and that the entities that provide budgetary support new communities that may emerge.

2. The discussion should be based on concrete data a not on speculation

As noted above, the proposal of these communities is not based on concrete data or true cases that merit rapid legislative action at the international level. Preventive work without concrete data can generate unexpected consequences, creating greater uncertainty.

Furthermore, working on concrete data is important since the lack of certainty makes it difficult to manage power, identify allies, and define strategies, which in the long run generate instability in institutions. (Hass, 1992, p. 14) Likewise, international organizations must be aware that regardless of what these communities say, which may or may not be true, the decisions about what to do are political and fall to them. (Hass, 1992, p.11)

In this sense, it is preliminarily recommended that companies and the technical community provide accurate information about the technological advances they are making. In particular, it is suggested that companies open dialogue channels to allow public accountability.

Additionally, for the future, it is recommended that the impact of the speeches of these communities be evaluated. In this study, it was possible to identify that on the one hand, people who have a medical condition that prevents their brain from connecting with other parts of the body need these technologies to have

autonomy. This is a situation that must also be evaluated using concrete data and should be analyzed jointly with the concern of human beings losing autonomy due to neurotechnologies.

CONCLUSION

This study has allowed us to know and identify three epistemic communities that do important work at the local and international level. Although these communities that are part of a practical community have managed to introduce into the public debate the need to talk about new rights to protect human cognition, they have not managed to have enough influence in the international forum for their proposal to be accepted as is. It has been shown that the debate on the impact of neurotechnologies is present in various international forums and each one is opting for different alternatives. However, while this process takes place and epistemic communities participate in it, two problems are emerging: the lack of participation of civil society and the private sector and the lack of concrete data on the impact of neurotechnologies. It is therefore recommended to address these problems as soon as possible so that the decision made is the most beneficial for humanity.

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