46th Closed Session of the Global Privacy Assembly

November 2024

Resolution on principles regarding the processing of personal information in neuroscience and neurotechnology

This Resolution is submitted by the sponsors on behalf of the Digital Economy and Society Working Group

SPONSORS:

- National Institute for Transparency, Access to Information and Personal Data Protection (INAI), Mexico – GPA Chair
- National Commission for the control of Personal Data protection (CNDP), Morocco – DESWG Chair
- Agency of Access to Public Information (AAIP), Argentina

CO-SPONSORS:

- European Data Protection Supervisor (EDPS)
- The Information Regulator of South Africa (IRSA).

The 46th Global Privacy Assembly 2024:

WHEREAS rapid progress in neuroscientific research and neurotechnologies has significantly expanded our understanding of the human brain, enabling breakthrough discoveries in the prevention and treatment of disease for the well-being of humanity.

The concepts of 'neurodata' and 'neurotechnology' are still subject to different definitions,

AGREES *nevertheless,* that, for the purpose of this Resolution, the following definitions are used:

- ***Neurodata:*** data relating to the functioning, activity or structure of the human brain of an individual that includes unique information about their physiology, health, or mental states[1] that allow their identification or make them identifiable.

- ***Neurotechnology:*** devices and procedures used to access, capture, monitor, transmit, process, investigate, assess and/or manipulate the structure, activity and function of the neural systems of natural persons[2].

TAKING NOTE OF the rapid and significant advances in neurotechnologies, neuroscience, and neurodata collection, as well as their technologically possible increasing integration into various aspects of society, it highlights the critical importance of these disciplines in improving human health, enriching understanding of the brain, and the potential to revolutionize fields also due to artificial intelligence. However, the processing of personal data deriving from the use of neurotechnologies raises concerns and the need to be assisted by solid and appropriate safeguards to protect fundamental rights and dignity of individuals involved. Moreover, the possible use of neurotechnologies beyond the medical treatment and scientific research sectors in compliance with applicable sectoral and ethics standards raises further crucial considerations from a human rights perspective. These developments promise profound transformations in the way we live, work, and learn and underscore the need for legal and ethical consideration and careful regulation to ensure they are only used in ways that benefit society.

UNDERSTANDING that the information derived from neuroscience can influence one's perception of oneself and social interactions, resulting in a necessity of its use with a sense of responsibility and respect for fundamental human rights.

AGREEING on the importance of commitments towards the establishment of legal requirements and ethical practices that protect people against any form of discrimination, stigmatization and manipulation based on their neurodata.

ACKNOWLEDGING that the potential misuse of neurotechnologies and neurodata, could interfere with individuals' brain activity, affecting their personality and identity in fundamental ways, which could lead to detrimental and long-lasting consequences for affected individuals.

DETERMINED to ensure that scientific progress in neuroscience and neurotechnology is conducted in a manner that respects and protects the rights and interests of individuals; it is crucial to consider every advancement with an unwavering commitment to human

[1] definition corresponding to 'Personal brain data' in the OECD Recommendation on Responsible Innovation in Neurotechnology

[2] Definition from the OECD Recommendation on Responsible Innovation in Neurotechnology

dignity, in particular human rights, and ethics to ensure that technology serves to benefit human well-being rather than the other way around.

RECOGNIZING the imperative need of legal and ethical frameworks that are not only robust and effective, but also dynamic and adaptive, able to respond to technological developments and the complexities of the modern neuroscience landscape.

DETERMINED to establish a culture of respect and responsibility around the handling of neurodata, to prevent any form of abuse or discrimination that may arise from its inappropriate treatment.

ACKNOWLEDGING the unique and exceptional sensitivity of neurodata, which has a direct and profound correlation with cognitive and affective states, which reflects people´s personal experiences and emotions. It should be considered that given the special sensitive nature of this data, which reflects the subtleties of the human mind, its processing should be prohibited unless certain conditions are met and specific safeguards are in place in compliance with the protection of human rights, the applicable legal framework and the privacy and data protection rules and principles, and always for the benefit of the concerned individuals or group of people.

EMPHASIZING that any technological advancement should be made with the utmost consideration for personal autonomy and the integrity of the human being.

EMPHASIZING the critical importance of protecting personal data, including neurodata, from unauthorized access, use, modification or exploitation; it is vitally important to implement robust security measures and clear policies that ensure the confidentiality and integrity of each individual's sensitive information and to avoid any forms of discrimination towards individuals and groups of individuals.

EXPRESSING deep concerns about the significant risks to all human rights, including privacy, data protection as well as physical and mental integrity, posed by the widespread use of neurotechnologies and the collection and processing of neurodata; the imperative need to address these issues with the utmost seriousness is emphasized. The potential of these technologies to invade the most sacred intimacy of the human being, the brain, requires constant vigilance and the implementation of robust safeguards, including prohibitions in some cases.

EXPRESSING serious concerns on certain uses of advanced data processing methods (including artificial intelligence and other emerging technologies) to analyse neurodata, beyond the medical treatment and scientific research fields in compliance with applicable sectoral and ethics standards, making technically possible legally questionable exploitation

of neurodata and of inferences therefrom, for instance for law enforcement, screening of migrants and asylum seekers, targeting advertising as well as by private entities for workplace or commercial surveillance.

RECOGNIZING the transnational nature of neuroscience research, data sharing, and neurotechnology development; international collaboration is highlighted as a fundamental pillar for progress in this field. Global interconnectedness facilitates unprecedented synergy between scientists, institutions, and countries, enabling faster and more effective breakthroughs, highlighting the importance of fostering a culture of open and ethical exchange of knowledge and technologies based on existing legal frameworks, ensuring that the benefits of neuroscience and neurotechnologies are accessible and used equitably around the world.

AFFIRMING the importance of the creation of strategic alliances that promote the exchange of knowledge and best practices regarding neuroscience and neurotechnologies between experts in the field as well as Data Protection Authorities and other related stakeholders, to ensure that the development and application of neurotechnologies are carried out with the greatest respect for human rights, integrity and dignity.

CONSIDERING the potential of cross-border data flows in the context of neurodata, and the implications this has for the protection of privacy, personal data, dignity and human rights; the urgency of addressing these global challenges is recognized. The special sensitive nature of neurodata, which can reveal intimate aspects of the human psyche, demands meticulous attention and international cooperation to establish appropriate legal requirements, standards and practices -including possible bans- that respect the dignity and autonomy as well as the fundamental rights of individuals, regardless of borders.

TAKING NOTE OF some fundamental neurorights defined by the Neurorights Foundation[3], that seek to establish ethical and legal limits to protect the human mind against the advance of neurosciences and neurotechnologies, which are **rights to personal identity[4], free will[5], mental privacy[6], equal access to neurocognition[7] and to protection against bias and discrimination[8].**

[3] Available for consult through the following link: https://neurorightsfoundation.org/mission.
[4] Protects against technological alteration of the sense as individual. In other words, it seeks to preserve our identity and prevent technology from interfering with our perception of who we are.
[5] Safeguards the freedom to make decisions without outside interference.
[6] Ensures the confidentiality of neural thoughts and data.
[7] Promotes equality in the improvement of brain capacities.
[8] Defends against the misuse of technology that may induce prejudice or discrimination.

TAKING NOTE OF some global initiatives towards the regulation on neurotechnologies, that served as reference points for the present Recommendation, such as: the OECD Recommendation on Responsible Innovation in Neurotechnology, December 2019, the Declaration of the Inter-American Legal Committee on Neuroscience, Neurotechnologies, and Human Rights, August 2021; OEA- Inter American Declaration of Principles Regarding Neuroscience, Neurotechnologies, and Human Rights, March 2023; Neurodata Statement Iberoamerican Data Protection Network, September 2023; Expert report on "The privacy and data protection implication of the use of neurotechnology and neural data from the perspective of Convention 108" by Dr. Eduardo Bertoni and Prof. Dr. Marcelo Ienca, June 2024.

TAKING ALSO NOTE of the European Convention on Human Rights, the Convention for the protection of individuals concerning automatic processing of personal data: ETS No. 108 of the Council of Europe, Charter of Fundamental Rights of the European Union, the General Data Protection Regulation and the AI Act, which outline certain provisions regarding neurorights and the use of neurodata.

RECALLING the resolution in 2023 of the GPA "*Achieving global data protection standards: Principles to ensure high levels of data protection and privacy worldwide"* that updates the Madrid resolution, which was adopted by the GPA in 2009, and which specified a set of data protection and privacy principles and rights, many of which remain familiar today, the following is issued:

The 46th Global Privacy Assembly emphasises the need for advances in neuroscience and neurotechnological applications **should** uphold human rights and dignity while respecting privacy and personal data protection, and with this Resolution **the importance of the following:**

- Highlights that Data Protection laws offer a robust framework to address the challenges posed by neurotechnologies in relation to the processing of personal data, which must be fully complied with when developing and deploying these technologies. However stakeholders should promote, if and when appropriate, further instruments to increase the level of protection for persons whose neurodata would be processed, as these would strengthen and complement the compliance with privacy and data protection principles in the implementation of neurotechnologies.
- Sets forth the following principles to guide the responsible handling of personal data in neuroscience and neurotechnology, with the aim of fostering trust, accountability, and respect for privacy and personal data protection in this rapidly evolving field.
- Establishes comprehensive principles for the ethical and lawful processing of personal information within the domain of neuroscience and neurotechnology. These principles apply to all individuals, organizations, and entities engaged in the collection, processing, or utilization of neurodata and related personal data, adhering to sectoral and ethics applicable standards.

Provisions related to Principles:

In this regard, the 46th Global Privacy Assembly endorses the existing data protection and privacy principles as core elements for the processing of personal data in neuroscience and neurotechnology, the aforementioned, taking into consideration the Resolutions on Achieving Global Data Protection Standards: Principles to Ensure High Levels of Data Protection and Privacy Worldwide, we can highlight the following principles:

1. **Lawful basis for processing and consent**

Where the use of neurodata does not breach human dignity and fundamental rights, valid consent from individuals before processing their neurodata is crucial as this ensures that individuals have control over their data and understand the purpose of its use for the access to the collection of their brain information. It remains relevant, that any form of consent must be revocable at any time, particularly in the case of vulnerable people[9].

.

Moreover, it must be taken into consideration that in certain cases such as children and adolescents, people with disabilities, people with limited decision-making capacity, and other vulnerable and marginalized social groups consent may not be the appropriate legal basis to rely on. Consequently, data controllers will need to consider the possibility of relying on any other legal basis.

Consent forms and privacy notices should be based on information relevant for making informed decisions, as well as presented in plain language, avoiding technical jargon, for which raising public awareness is a crucial strategy, given the technicality of the topic itself, and individuals should have the opportunity to ask questions and withdraw consent at any time.

2. **Purpose specification and use limitation.**

Researchers, practitioners, and institutions working with neurodata should adhere to ethical guidelines that are based on privacy and security legal frameworks and process personal data on a valid legal basis, ensuring that neurodata is collected only for specified, explicit, and legitimate purposes, and not further processed in a manner incompatible with those purposes.

[9] However, there might be cases in which informed consent is not the appropriate legal basis for the processing of neurodata, this must be taken into account, ensuring that the correct and most appropriate legal basis is used, to ensure that individuals have control over their data and their data rights are protected.

For this reason, as well as to ensure human dignity and fundamental rights, as a rule neurodata should be used for the benefit of the concerned individuals, groups of people or society, including for medical, research and other public interest, and in compliance with all privacy and data protection conditions and safeguards. The use of neurodata for instance for commercial purposes or in the context of legal processes or insurance should be given particular regulatory scrutiny given the potential harms and risks. However, organizations should be aware that the use of neurodata for said purposes may not be allowed in certain jurisdictions.

3. Data minimisation

Only the minimum necessary neurodata should be collected and processed for the intended purpose. Neurodata that is no longer necessary for serving the intended purpose should be deleted.

For this should be taken into consideration the respective legal frameworks where applicable, as well as the historical data and the lifecycle of the data under the intended purpose for the data minimisation which will ultimately depend on the process and or task being undertaken in the field of neurotechnology.

4. Accuracy

Neurotechnology developers and researchers should implement robust validation of the methods used to collect reliable data and, through analysis, arrive at reproducible outcomes and adjust measuring instruments to ensure the accuracy of the data collected from neuroimaging devices, brain-computer interfaces, and other neurosensing tools, as well as the mitigation of inaccuracies arising from technical limitations, environmental factors and individual variability.

Moreover, neuromodulation or neurostimulation must be taken into account, which will allow those aspects of how accuracy should or can be measured over time to be established, especially when brain waves are altered using this technology.

5. Transparency

Neurotechnology developers and practitioners should implement **clear and informed consent processes** that outline the nature of data collection, the intended use of personal information, and any associated risks or benefits.

Clear information should be provided by the controllers to the public and research participants about the collection, storage, data retention, processing, and potential use of personal brain data collected for **health purposes.**

6. Security

Considering the risk of potential misuse of neurodata appropriate and particularly robust security measures should be adopted.

Governments and relevant scientific bodies should promote industry or research-based best practices in enhancing security and privacy when neurodata are processed.

Public and private organisations and individuals who play an active role in neurotechnology innovation, including research, development uptake, and use, should protect personal data gained through the application of neurotechnology from unauthorised and or unlawful use, including the use of data access agreements when appropriate, as well to promote confidentiality and privacy and mitigate security breaches, including the implementation of state-of-the-art security standards, as well as risk management.

7. Proactive measures

Privacy-enhancing technologies should be employed to safeguard individuals' personal data and in particular sensitive information. This includes implementing privacy by design and by default principles. Regular assessments of the impact of neurotechnologies on privacy and other rights and freedoms of persons concerned must be conducted.

8. Rights of data subjects

Ensure that data subjects can exercise their rights when their personal information is used in neurotechnology. This way, stakeholders can foster trust, accountability, and ethical practice in the collection, analysis, and utilization of neurodata. Upholding these rights is essential for promoting respect for individual autonomy and safeguarding privacy, data protection and other fundamental rights in the rapidly evolving field of neurotechnology.

Promote opportunities for individuals to choose how their personal data is used and shared and ensure the compliance of controllers with the existing rights of the data subjects such as access, rectification, erasure and opposition to the processing of personal data as well as to oppose to automatic decision making and profiling.

9. Accountability

Recognizing the complex ethical and societal implications of neurotechnology and the processing of personal neurodata, it is imperative to establish robust accountability mechanisms, such as but not limited to privacy or data protection impact assessments, independent audits, training, education and awareness-raising, privacy management programs, and certifications, among others to ensure responsible and ethical practices throughout the entire lifecycle of neurodata processing, from collection to storage, analysis, and dissemination, guaranteeing traceability not only of data collected and processed but also of medical procedures involving neurotechnology.

10. Special Categories of Data

Given the sensitive nature of neurodata, high standards protections should apply to its processing, similar to other special categories of personal data (e.g., health data).

Most forms of neurodata constitute highly sensitive personal data. In this sense its processing should be prohibited unless certain conditions are met; given that neurodata would in most cases constitute health data, and when allowing the unique identification of a person would constitute a permanent form of biometric data, they should be treated as highly sensitive personal data. Their processing, when not prohibited, should be subject to reinforced additional safeguards and controls and only be allowed under specific conditions as outlined in applicable data protection laws.

11. Ethical Considerations

Emphasize the importance of upholding ethical standards in all aspects of neuroscience and neurotechnology research and application.

12. International Cooperation

Member states should collaborate to establish common standards for the responsible use of neurodata, making joint efforts to prevent harmful practices while promoting scientific discovery, including regular impact assessment and audits such as those related to security to identify and mitigate potential risks associated with neural data processing.

13. **Vulnerable Groups**

The impact of neurotechnology on children and adolescents, people with disabilities, others with limited decision making capacity and other vulnerable and marginalized social groups may be especially serious and their neurodata may be particularly sensitive. Therefore, proactive measures should be deployed to promote accountability in order to support the exercise of these individual's rights taking in consideration all the aspects linked in all principles and enhanced measures.

This is why, the 46th Global Privacy Assembly therefore resolves to:

Commitment to Legislation and Privacy:

- **Call to legislators and policymakers**, where necessary and appropriate, to coordinate their efforts in relation to neurotechnologies and call all its members and stakeholders to advocate in favor of the implementation of the principles, rights and other elements set forth in this resolution in order to ensure the responsible advancement of neurotechnologies, while safeguarding privacy and personal data, without losing focus on the application and compliance with the legislation
- **Ensure that the development of neurotechnologies and neuroscience complies with the existing Data Protection Frameworks:** to safeguard the dignity, autonomy, privacy and personal data protection of individual's.
- **Encourage legislators and policymakers to lay down, where appropriate, clear prohibitions** of uses of neurodata in breach of human dignity, taking into account the new technological advancements (as it is the cases for instance in the field of biomedicine), aiming at protecting the dignity and identity of all human beings and guarantee respect for their rights and fundamental freedoms.

Promotion of Public Awareness and Education:

- **Promote public awareness and education** on the ethical considerations, the potential risks associated with the use of neurotechnologies, the collection and processing of neurodata.
- **Encourage interdisciplinary research and collaboration** to address the ethical, legal, and social implications of advances in neurotechnologies and neuroscience.
- **Address the challenge of explaining a highly technical topic** such as neurotechnology in a plain, easily understandable language and in an accessible way to the public.

Development of Guidelines and Dialogue:

- **Facilitate dialogue among member authorities, experts, and stakeholders** to develop guidelines and recommendations for the ethical use of neurotechnologies and the protection of personal data.
- **Promote** the continue defining key areas and definitions within the topic in the respective standards, guidelines, or other instruments.
- **Include civil society, public authorities, law enforcement organizations, researchers, scientists, academics**, among others, in dialogue and policy development.
- **Promote the development** and publicise guidance for organisations and the public in the matter.

Rights of data subjects and Training of staff:

- **Urge neurotechnology developers, providers, and deployers** to safeguard data protection and privacy, which is recognized as a universal human rights.
- **Encourage training for employees and staff** by neurotechnology developers, providers, and deployers.
- **Strengthen the rights of data subjects**, including the right to be informed about how their personal data is used, the right to delete or rectify and to object the processing, and not to be subject to purely automated decisions.

International Cooperation and Standards:

- **Promote international cooperation and exchanges of best practices** in the regulation and governance of neurotechnologies and neuroscience.