Data Control and Neurotechnology: The Grain Case

Policy Brief Prepared for The Electronic Privacy Information Centre (EPIC) Leadership & Senior Staff

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Executive Summary

- The Grain is an invasive form of neurotechnology that raises ethical concerns about data control in relation to users' privacy, freedom, and identity.
- Neurotechnology remains largely unregulated except in two countries: Spain and Chile.
- EPIC has a mandated duty to champion the rights of neurotechnology consumers through research and advocating for regulation.

Introduction

Over the last two decades, **\$19 billion** has been invested into neurotechnology companies globally.¹ Despite this, the industry remains largely unregulated, especially in the protection of brain data. The <u>Electronic Privacy Information Centre (EPIC)</u>, as a leading international public interest research group focused on protecting privacy in the information age,² is in a key position to address the many ethical concerns about neurotechnology as well as the lack of regulation to protect potential consumer use.³ Using the neural implant device called "The Grain" as a case study, this policy brief provides a review of neurotechnology policy and explores options for EPIC's advocacy stance.

Background: The Grain and Neurotechnology

The "Grain" is a neural implant device that records people's audiovisual senses, allowing a person to re-watch their memories through their eyes or on a screen in a process called "redo".⁴ Screen "redos" allow people other than the user to quickly view the memories in as little as a few seconds.⁵ Recalled memories for "redo" viewing can stretch back as far as several years in the past.

The Grain is not the only invasive neurotechnology under development. There is also the Neuralink, designed by Elon Musk.⁶ Neurolink works by directly connecting with neurons in the brain, collecting these neuron signals, and using these signals to directly control digital devices.⁷ Neurolink has yet to start clinical trials but experts have already cited safeguard brain data as a top

ethical concern.⁸ Meanwhile, neuro-technological devices, notably much less advanced and intrusive than the "Grain", have already penetrated into the consumer marketplace. Mostly in the form of headsets (e.g, "Muse" by InteraXon and "Insight" by Emotiv Systems), individuals can use them to monitor their well-being, optimize brain fitness, or to play virtual games.

Despite the well intentioned objectives for these devices, it has been reported that their privacy and security standards are controversial with incidents including sensitive data leakage to brain spyware (e.g, addresses and PIN numbers) and unknown control over data.⁹ These privacy concerns are already transpiring from much less invasive neurotechnology which shows how crucial privacy regulation is needed before the "Grain" and similar products like Neurolink enters the market.

Stakeholders

Direct Stakeholders

- 1. EPIC as the forerunner to lobby privacy concerns
- 2. Consumers of neurotechnology that have the potential to be affected by privacy risks from the "Grain" technology
- Neurotechnology companies that are developing the "Grain" and other devices like it

Indirect Stakeholders

- 1. National governments and international organizations who may eventually have to regulate neurotechnology
- 2. Government agencies who may choose to use the Grain for security and policing purposes
- 3. Other neurotechnology ethics advocacy groups

The Current State of Policy

There currently is **no legally-enforced international policy directly addressing neurodata protection and privacy as it is still a nascent area of regulation**. As a consequence, the rapidly expanding neurotechnology sector is collecting large volumes of data without regulation.¹⁰ However, a variety of stakeholders have expressed growing concerns regarding neurotechnology regulation and have proposed ethical guidelines regarding neurodata.

Most notably, the <u>OECD Recommendation on Responsible</u> <u>Innovation in Neurotechnology</u> lists "safeguarding brain data" as one of its key nine principles.¹¹ In this regard, the OECD places informed consumer consent at the heart of ethical neurotechnology legislation. It also recommends that users have some control over "how their data are used and shared, including

¹ Yuste, Genser, and Herramann, "It's Time for Neuro-Rights," 157-158.

² Electronic Privacy Information Centre, "EPIC - Electronic Privacy Information Center."

³ Ienca, Marcello, Pim Haselager, and Ezekiel J Emanuel. "Brain leaks and consumer neurotechnology," 805.

⁴Wikipedia Contributors. "The Entire History of You.".

⁵ "Grain," Black Mirror Wiki.

 $^{^{\}rm 6}$ Johnson, Walter G.,& Lucille M. Tournas "Elon Musk Wants to Hack Your Brain." $^{\rm 7}$ Neuralink, "Neuralink, "

⁸ Ali Said et al., "Emerging Neuralink Brain Machine Interface Technology," 40–41.

⁹ lenca, Marcello, Haselager, and Emanuel, 806.

¹⁰ lenca, Marcello, Haselager, and Emanuel, 805–810.

¹¹ OECD, "OECD Recommendation on Responsible Innovation in Neurotechnology."

options for accessing, amending and deleting personal data."¹² In addition to protecting consumer privacy through "rigorous security standards," the OECD also argues that both the way brain data is shared and used, as well as medical procedures involving neurotechnology be monitored.¹³

Complementing the OECD recommendation, research conducted by legal and scientific experts at the Centre for International Relations and Sustainable Development (CIRSD) argue that the human rights of (mental) privacy and free will are crucial to the ethical regulation of neurotechnology and brain data.¹⁴ In this regard they advocate for legislation specifically addressed to protecting mental privacy and freedom in relation to neurotechnologies on the basis that existing international human rights laws only partially cover certain neurotechnology human rights issues, and remain insufficient.¹⁵ In addressing this policy gap, five "neuro-rights" are proposed: the right to identity; the right to agency/freedom; the right to mental privacy; fair access to neurotechnology and; protection from algorithmic bias.¹⁶ Unfortunately, uptake of these neuro-rights are limited on a state-level, with only two cases. Chile has amended its Constitution to protect neuro-rights, while Spain has passed its Digital Rights Charter.¹⁷ Therefore, CIRSD experts argue for the creation of a specialized UN agency to steer the global regulation of neurotechnology and protection of neuro-rights.

Policy Implications: Data Security

The way in which technologies like the Grain collects brain data has been coined by ethics experts as "lifelogging," or "the act or process of capturing and storing the totality of one's experiences, thereby creating a personal, searchable archive of one's life."¹⁸ The result of lifelogging is brain data, which is deeply sensitive information, and carries heavy implications around privacy, freedom, and security identity.¹⁹ Lifelogging can have positive benefits, such as monitoring of medical conditions and memory assistance.²⁰ However, Lifelogging can have serious risks, such as abuse of brain data.

A lack of sufficient data control protections can result in brain data being stolen through "brain hacking" by access to platforms of sensor data storage, analysis and visualization.²¹ Once hacked, this data can be abused in a variety of ways, ranging from mining deeply personal information such as biomarkers of mental illness

- ¹⁸ Postma, Marleen, " The Ethics of Lifelogging 'The Entire History of You'," 116.
- ¹⁹ Paz, Abe Wajnermanl. "Is Mental Privacy a Component of Personal Identity?"

or personal beliefs for commercial marketing purposes, to draconian neuromonitoring by state security agencies.²²

Privacy & Freedom

With the Grain implanted beneath the skin, it is difficult to remove and is highly intrusive, raising concerns over privacy and freedom. The Grain can be used by government officials as a means of **security screening**. For example, the quick replay screen function can be used to process travellers at an airport to see any suspicious activity they may have recently conducted; it could also be used in **criminal investigations** as proof of guilt. Secondly, it is unclear whether this device can be used for further, **constant memory surveillance**, intruding on freedom of thoughts and actions.

Lastly, the Grain contains a "redo" lip reading feature that allows the user to know what others are saying if the Grain captures video (but not audio) of people talking, presenting **privacy concerns for both the user and those around the user.** Social norms around trust and expected privacy may also be negatively impacted.²³ The passive nature of lifelogging data collection poses high risks for the capture of private information of the user and others around the user.²⁴ Also, since most brain data is unconsciously created, **a person may "unknowingly or unintentionally reveal brain data while under surveillance.**"²⁵ Therefore, mental privacy is even more sensitive and takes on further nuance beyond the already existing international human rights law around privacy.

Identity Security

Since the memories are digitally stored somewhere (e.g., the "cloud"), the data is susceptible to hacking or theft, posing severe identity security risks. Memories are highly personal and reveal a lot about a person's identity which make tempting blackmail material, among other concerns. This data could be used to create profiles identifying patterns of behaviour to an unnerving degree, and using such data to predict further actions. It is unclear who has access to this personal data and how they manage it.²⁶ Paz (2021) points out that several patients who are undergoing neurotechnological treatment in the form of deep brain stimulation (DBS) are most concerned with the potential threat to their identity. Paz argues that in order to address this concern, it is important to understand that "mental privacy is the psychological basis of privacy" and underlies the construction of our identities which could be left in a vulnerable position without regulation.²⁷

¹² OECD, 8.

¹³ OECD, 8.

¹⁴ Yuste, Genser, and Herrmann, 160.

¹⁵ Yuste, Genser, and Herrmann, 160.

¹⁶ Yuste, Genser, and Herrmann, 160-161.

¹⁷ Yuste, Genser, and Herrmann, 161.

²⁰ Postma, 117.

²¹ lenca, Marcello, Haselager, and Emanuel, 807-808.

²² lenca, Marcello, Haselager, and Emanuel, 807-808.

²³ Postma, 117.

²⁴ Gupta, Rashmi, Martin Crane, and Cathal Gurrin. "Considerations on Privacy in the Era of Digitally Logged Lives."

²⁵ Yuste, Genser, and Herrmann, 159-160.

²⁶ Lanzing, Marjolein: The (Re)Collection and Future Use of Your Data, 85.

²⁷ Paz, 3.

Analysis: Assessment of Options

EPIC's mandate is to advocate for emerging technology ethics issues, including the serious ethical implications raised in the case of the Grain. In working for further protection of neurotechnology ethics, EPIC can push for three different approaches: promoting further research, facilitating the development of international regulation, and advocating for a temporary ban of neurotechnologies. These three options are discussed in detail below and analyzed according to criteria (see Box 1). Assessment of the three possible advocacy topics is assessed according to the criteria in Table 1.

- Further Research: Neurotechnology is an evolving field that requires further analysis to gain a better understanding of its implications. A
 research committee is needed to be formed in order to address the concerns with neurotechnology. EPIC is capable of conducting its
 own research, but also can bring together other industry experts across private sector, academia, and government to scale the
 development of neurotechnology ethics as the industry and technology rapidly evolves and develops.
- 2. Regulation: Despite the commercial use of neurotechnology expanding rapidly, the technology remains largely unregulated with only unenforceable policy (e.g., OECD Recommendation) in place. Legal frameworks should be implemented to address the large gaps in both international and national laws around neurotechnology development and usage. As a leading advocacy group, EPIC is in a unique position to assemble existing resources at research organizations, government agencies, and international organizations, and utilize this aggregation of resources in providing expert advice, litigation, and lobbying for increased neurotechnology regulation
- 3. Temporary Neurotech Ban: EPIC can work to eliminate all access to invasive neuro-tech using litigation on the basis that it poses a privacy threat to users. Until a research committee examines the concerns with neurotechnology and regulation is then implemented, it is suggested that a temporary ban should be placed on an international level, halting all development and sales of invasive neurotechnology.

Box 1: Decision Criteria

- 1. Benefit: what benefit(s) would this alternative provide to protecting Grain users?
- 2. Harm: what potential harm(s) to Grain users would this alternative raise?
- 3. Viability: how likely is this alternative to succeed, taking into consideration the following metrics:
 - Legality: does it comply with international ethics around neurotechnology? How easily can it be passed into law?
 - Political acceptability: how likely is this course of action to be accepted by governments?
 - Corporate acceptability: how likely is this course of action to be accepted by neurotechnology corporations

Table 1: Options Assessment Matrix

Option	Assessment by Criteria				
	Benefits	Harms	Viability		
1. Research	Obtaining a well-developed research foundation on this issue is crucial to become well equipped for the execution of possible regulation in the future	Prolongs the start of developing regulation which in result could harm the Grain's initial consumers if made public before any ethical protections are established	Research is legal and is low-risk in terms of political and corporate acceptability		
2. Regulation	Ensuring the secure use of neurotechnology by pushing for companies and	Potential political and commercial (businesses) disagreement resulting in no security or	There is a lower-risk of success compared to research, but existing non-enforceable policy by OECD as well		

		governments to abide by rules for developing neurotechnology and accessing sensitive data.	compelling companies to find a way to hide their data misuse. This would result in the continuing lack of ethical protection for Grain users	as basic ethics generally addressed in general human rights law provide a strong legal foundation for increased regulation. Medium risk for political and corporate acceptability.
3. Te B	emporary an	Allows more time to work on developing a consensus on the next steps to take in order to protect users.	Neurotechnology has many benefits for users as previously discussed (e.g., health monitoring). A temporary ban may become hampered in bureaucracy, extend indefinitely, and result in an unneeded loss of access for consumers.	The possibility of a total ban (even a temporary one) on neurotechnology is highly improbable both politically and in the corporate sphere. Legally, it would be very difficult to pass and enforce an international ban. Any advocacy or litigation by EPIC is unlikely to succeed.

Recommendations

Of the three alternatives assessed, Regulation presents the best benefits for neurotechnology users while remaining viable. It is strongly suggested that EPIC advocates for non-enforceable policy by OECD as it presents medium risk of acceptability for the direct stakeholders involved. While further research is clearly the safest option, it is not nearly enough on its own to truly protect consumers. Without any ethical protections, initial users of the Grain could be at extreme risk of their data security. Meanwhile, the viability of a temporary ban is extremely low in the political and corporate sphere and ultimately, this sort of legislation would be unfeasible for EPIC to endorse.

While regulation still carries the risk of being ineffective and ignored, it is the mandate of organizations like EPIC to continue advocating for whatever legal protections possible for vulnerable users of emerging technologies like the Grain. Therefore, **advocating for regulation while still continuing research is the best option for EPIC moving forward**. Phases 1 and 2, elaborated below, should launch simultaneously.

PHASE 1: Research

EPIC should accelerate research on neurotechnology ethics by facilitating areas for discussion among experts through the creation of an advocacy research committee. Research conducted by the committee should be grounded in both the OECD Recommendation and the five "neuro-rights" proposed by the CIRSD (see Box 2), and endorsed in Chapter 5, Article XVVI of Spain's <u>Carta Derechos Digitales (Spanish Charter of Digital Rights)</u>.²⁸

Box 2: CIRSD Neuro-Rights Proposal

- 1."the right to identity, or the ability to control both one's physical and mental integrity
- 2.the right to agency, or the freedom of thought and free will to choose one's own actions

3.the right to mental privacy, or the ability to keep thoughts protected against disclosure

- 4.the right to fair access to mental augmentation, or the ability to ensure that the benefits of improvements to sensory and mental capacity through neurotechnology are distributed justly in the population
- 5. the right to protection from algorithmic bias, or the ability to ensure that technologies do not insert prejudices."

Source: <u>CIRSD</u>

The committee would tackle three key issue areas:

- Neurodata Governance (collection, access, sharing, storage, deletion)
- Freedom and Privacy
- Identity Security

²⁸ Yuste, Genser, and Herrmann, 161.

There are several neuroethics organizations that exist already to address the ethical, legal, policy and social implications of neuro-technological devices. The following, geographically-diverse programs should be consulted: the <u>International Neuroethics Society (INS)</u>, the <u>Future of Privacy Forum (FPF), IBM Policy Lab</u>, and the <u>Oxford Centre for Neuroethics</u>.

The results of this research committee will help inform EPIC's expert advice given to policymakers and lawmakers in Phase 2.

PHASE 2: Regulation

In alignment with CIRSD's proposal, EPIC should **lobby for the creation of neurotechnology special agencies** in various international organizations like the United Nations and the OECD to help begin regulation. Revision of international human rights law to explicitly address privacy, freedom, and identity issues arising from the Grain and other invasive neurotechnologies is also key. The existing OECD Recommendation on Responsible Innovation in Neurotechnology is a strong building block, supplemented overtime by the research results from Phase 1. Since EPIC is U.S.-based, pushing for national legislation through targeted litigation in line with EPIC's <u>Open Government, Surveillance</u> <u>Oversight</u>, and <u>Consumer Privacy Advocacy projects</u> is also key. The U.S. is a major player in global politics and national neurotechnology legislation may help promote neurotechnology regulation internationally

The main priorities for legal action that EPIC should lobby for are as follows:

- Limit company's access to sensitive data (identity security)
- Prohibit the sharing of sensitive data with third-parties
- Pose strict security standards on stored data to prevent hacking and mis-use
- Create legal framework around government access and usage of brain data upheld in international human rights law
- Requiring sandbox testing programs for the safe development of neurotechnologies

EPIC should endorse a **public-private partnership** approach to regulation in order to facilitate constructive negotiations for regulating neurotechnologies. Neurotechnology industry leaders (e.g, The Grain, Neurolink) must be consulted. Organizations that should be consulted in advocating for a regulatory framework include the OECD (given their existing Recommendation on neurotechnology ethics), CIRSD, and other technology ethics advocacy experts like the INS. States who have already introduced laws upholding neurotechnology ethics (Spain and Chile) should also be key partners in the global political arena. Finally, community consultations with focus groups of neurotechnology users is key.

Conclusion

Invasive neurotechnologies like the Grain carries high ethical risks around data control with negative implications for the privacy, freedom, and identity security of consumers. Unfortunately, the industry is severely under-regulated both at state and international levels. EPIC, as a leading advocate for emerging technology ethics, has a duty to push for international regulation. The summary below summarizes our recommendations for EPIC to follow:

Summary of Next Steps for EPIC

- 1. Short Term: The concurrent formation of:
 - Expert research committee composed of diverse stakeholder groups (national governments, international organizations, researchers, academia, private sector, neurotechnology users)
 - b. International regulation lobbying group
- Medium/Long-Term: Integrate neurotechnology ethics dimensions into its current advocacy initiatives (Open Government Project, Surveillance Oversight Project, and Consumer Privacy Advocacy Project) and promote U.S. adoption of neurotechnology ethics through its existing targeted litigation mechanism
- Long-Term: Drawing on existing neurotechnology policy documents (OECD Recommendation, CIRSD "Neuro-Rights", Spanish Charter
 of Digital Rights), EPIC should unite and lobby current leaders in neurotechnology ethics (OECD, CIRSD, INS, Spain, Chile) for the
 creation of United Nations and OECD special agencies for neurotechnology ethics regulation

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