From: S22

Sent: Wednesday, 14 June 2023 9:09 AM

To: Humanrights Commissioner

Cc: s2

**Subject:** RE: Invitation to Neurotechnology and Human Rights Consultation

[SEC=OFFICIAL]

Hi <sup>s47F</sup>

Thank you for your email and my apologies for the delay in responding.

In relation to your query below, we would need to seek further internal clearance if the OAIC is to be identified with our earlier comments in any submissions so we are comfortable to operate under Chatham House Rules for the time being.

You have also sought permission in a separate email whether our comments could be shared with Wotton + Kearney to help inform their advice on the application of the Privacy Act to brain data. We are happy for our comments to be shared with our usual caveat that they are officer-level comments only. I note the Legal Services Directions require consultation with the Attorney-General's Department as the administering entity of the Privacy Act. We would also be interested in receiving a copy of the advice if you're able to share it with us.

Please let us know if you would like to discuss further.

Kind regards



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From: Humanrights Commissioner < humanrights.commissioner@humanrights.gov.au >

Sent: Tuesday, June 6, 2023 10:20 AM

Subject: RE: Invitation to Neurotechnology and Human Rights Consultation [SEC=OFFICIAL]

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Hi<sup>s22</sup> ,

Thank you and the OAIC team for your comments, they will be valuable for preparing our submission. During this process we operate under Chatham House Rules unless otherwise stated, I wanted to check whether the OAIC would like the be identified with the points you have made below?

Kind regards, s47F s47F

Executive and Research Assistant to the Human Rights Commissioner 
Australian Human Rights Commission

GPO Box 5218, Sydney NSW 2001

T

S47E(d)

@humanrights.gov.au W humanrights.gov.au

# Human rights: everyone, everywhere, everyday

We acknowledge the traditional custodians of this land, the Gadigal peoples of the Eora Nation, and pay our respects to their Elders, past, present and future.

You don't often get email from \$22 @oaic.gov.au. Learn why this is important

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# Good morning

Thank you for the invitation to participate in the AHRC's consultations to inform your response to the United Nation's Human Rights Council Advisory Committee's (UNHRCAC's) study on the impact, opportunities and challenges of neurotechnology. Unfortunately, the OAIC is unable to participate in the AHRC's online consultations on this occasion, but we have included some comments below for your consideration.

As a starting point the OAIC agrees with the AHRC's statement that while emerging technologies such as neurotechnology offer profound benefits to society, it is critical that they are developed and deployed with human rights at the centre. In Australia, and around the world, privacy is recognised as a fundamental human right and, accordingly, entities are required to comply with legislated privacy obligations when handling individuals' personal information to develop, deploy and use any new technology.

We note that question 10 of the UNHRARC's questionnaire asks whether national legislation on privacy and data protection covers mental privacy and/or personal brain data. While the Privacy Act does not provide for an explicit right to 'mental privacy' or coverage of 'personal brain data', the Privacy Act is principle-based legislation that establishes a technology-neutral and flexible framework for regulating how entities collect, use and disclose personal information in Australia. This means that it is adaptable to changing technology and environments, including emerging neurotechnology, and creates legal obligations that address the collection, use or disclosure of personal information in this technology.

'Personal information' is any information or an opinion about an identified individual, or an individual who is reasonably identifiable. What is personal information will vary, depending on whether a person can be identified or is reasonably identifiable in the circumstances. Information collected, used and disclosed by neurotechnologies may be considered personal information under the Privacy Act if it is information about an identified or reasonably identifiable individual.

The information collected, used and disclosed by neurotechnologies may also meet the definition of 'sensitive information' under the Privacy Act as in certain circumstances it may be considered health information. Sensitive information is subject to a higher level of protection under the Privacy Act.

We understand that the AHRC's submission to the UNHRCAC's study will build on the AHRC's submission to the Privacy Act Review. We therefore take this opportunity to highlight the following proposals from the Privacy Act Review that, if passed into legislation, may help to address many of the privacy risks and harms presented by neurotechnology:

- Amend the Privacy Act to require that the collection, use and disclosure of personal information must be fair and reasonable in the circumstances: An obligation for collection, use or disclosure to be fair and reasonable would require entities to proactively consider the foreseeable risks to individuals caused by information handling through neurotechnology, regardless of whether notice and consent was provided. In this way, it sets a baseline level of protection without placing a burden on the individual to consider and understand the collection notice or privacy policy of every neurotechnology device they may use. This test would be supported by factors which would require consideration of the kind, sensitivity and amount of personal information being collected, used or disclosure and the risk of unjustified adverse impact of harm, among other considerations. We consider this would be an important safeguard to address risks arising from how personal information in neurotechnology is collected, used and disclosed and its impacts.
- Require Privacy Impact Assessments (PIA) for activities with high privacy risks (any function
  or activity that is likely to have a significant impact on the privacy of individuals): A PIA is a
  systematic assessment of a project, which can assist in identifying potential impacts that a
  project might have on individuals, and sets out recommendations for managing, minimising or
  eliminating those impacts. Noting the potential of neurotechnology to significantly impact

privacy, organisations which offer neurotechnology products or services may need to conduct a PIA prior to commercialising their product or service, consider their privacy risks and impact, and develop management and minimisation strategies to address those risks and impacts. We consider this a well-developed method to address the privacy-related impacts of new technology and note our website contains guidance for entities on how to conduct a PIA.

• Strengthened consent requirements, which will require consideration of the capacity of people experiencing vulnerability: The Privacy Act Review final report proposes defining consent to provide that it must be voluntary, informed, current, specific, and unambiguous, and to clarify that consent is only valid if it is reasonable to expect that an individual to whom the organisation's activities are directed would understand the nature, purpose and consequences of the collection, use or disclosure of the personal. Such a provision would ensure that where vulnerability is identified, such as in the case of an individual with a disability, consent will only be valid where it is reasonable to expect that the individual understands the collection, use or disclosure of their personal information by neurotechnology they are consenting to.

Please let us know if you would like to further discuss the privacy implications of this technology, including the scope and application of the Privacy Act and the impact of the proposed privacy reforms.

# Kind regards



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From: s47F s47F s47E(d) @humanrights.gov.au>

Sent: Thursday, 22 February 2024 9:59 AM

To: \$22 Cc: \$22

Subject: RE: Expert Reference Group on Human Rights and Neurotechnology

[SEC=OFFICIAL]

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Hi s22

We completely understand and would like to thank you for considering the offer. We appreciate the ability to continue to engage with you on privacy issues.

I will send across the Background Paper to you both when it is published.

## Thanks

s47F s47F (he/him)

Human Rights Advisor (Business and Technology)

# **Australian Human Rights Commission**

Level 3, 175 Pitt Street, Sydney NSW 2000 GPO Box 5218, Sydney NSW 2001

Email: s47E(d) @humanrights.gov.au

From: s22 @oaic.gov.au>

Sent: Thursday, February 22, 2024 8:54 AM

Subject: RE: Expert Reference Group on Human Rights and Neurotechnology [SEC=OFFICIAL]

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# **Dear Patrick**

Thank you for the invitation to join the Expert Reference Group on Human Rights and Neurotechnology. Unfortunately, we are unable to join the Expert Group but we are interested in following the work of the AHRC in this space and continuing to engage with you in relation to privacy matters where possible. (copied) and I are the relevant contacts at the OAIC should you require assistance as this work progresses.

Kind regards s22



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From: s4E(d) @humanrights.gov.au>
Sent: Monday, February 19, 2024 3:20 PM

To: <sup>\$22</sup> < \$22 @oaic.gov.au>

Subject: Expert Reference Group on Human Rights and Neurotechnology [SEC=OFFICIAL]

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Dear s22

As part of our ongoing strategic engagement with human rights and neurotechnology, the Australian Human Rights Commission (**Commission**) is establishing a formal Expert Reference Group on Human Rights and Neurotechnology (**Expert Group**) to assist us with feedback on the direction of our work.

The Expert Group would be required to meet with the Commission via Teams on an 'as needs' basis to discuss strategic direction of our work and/or provide feedback on documents (e.g. a White Paper). The time commitment would be limited to ensure capacity is not an issue.

We anticipate that the Expert Group will be made up of 15 members from across academia, civil society, law and other stakeholders. All members of the Expert Group will likely be publicly acknowledged in any Commission products (e.g. reports), unless requested otherwise.

If this is something you would be interested in, please let us know! We look forward to your response.

Kind regards

s47F s47F (he/him)

Human Rights Advisor (Business and Technology)

# **Australian Human Rights Commission**

Level 3, 175 Pitt Street, Sydney NSW 2000 GPO Box 5218, Sydney NSW 2001

Email: s47E(d) @humanrights.gov.au

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# **Event brief**

# AHRC Neurotechnology Event

To:	Privacy Commissioner Carly Kind
Prepared by:	s22
Through:	
File ref:	D2024/018560
Date:	<b>Tuesday 18 June 2024</b> , 11:15 – 12.00 AEST (core session). Conference opens at 0945 and lunch is at 12 noon
Venue:	Room 202/203, University of Melbourne Law School, 185 Pelham Street, Carlton VIC.
Topic:	Neurotechnologies and Human Rights: Opportunities, Challenges and the Pathway Forward
Format:	In person. Commissioner Kind and other commissioners will speak for 10 minutes and then join in a panel discussion, hosted by Commissioner Lorraine Finlay.
Audience:	Industry, legal, academia, government and civil society, approximately 70. The event will be recorded and broadcast. Media are not expected to be present but may gain access to the proceedings.
Brief contents:	Attachment A: Event details

OAIC

Event contacts	Attach position		: Talking	points,	key fact	ts and	
	Attachment C: Background information						
	AHRC:	s47F	s47F		s47E(d)	,	
	s47F	s47F	, t: s47E(d)		E:		
	@humanrights.gov.au						
	OAIC:	s22	, s	22	@oaic	.gov.au,	
	s22						

# Attachment A: Event details

# **Event overview**

# About AHRC event

The Symposium forms part of the Australian Human Rights
Commission's ongoing strategic engagement with human rights and
neurotechnology, and will build on the recently published <u>Background</u>
<u>Paper</u> on this subject. The event will bring together experts and
stakeholders from government, business, the legal sector, academia,
and human rights specialists, to discuss the opportunities, challenges
and best pathway forward for regulating neurotechnologies.

The Symposium will include keynote presentations, break-out sessions to enable discussion in key thematic areas, as well as the **Regulatory Horizons - Considering Tomorrow's Challenges, Today** panel. The panel will see Commissioners speak about a neurotechnology challenge in their field for 10 minutes each. We have in mind that Commissioner Kind would focus on the privacy implications of neurotechnologies - for example, the protection of neural data. The panel will be moderated by our Human Rights Commissioner Lorraine Finlay.

# Panel: Regulatory Horizons: Considering Tomorrow's Challenges, Today

Time: 11:15 am - 12:00 pm Panellists:

- Robert Fitzgerald, Age Discrimination Commissioner, Australian Human Rights Commission
- Julie Inman Grant, eSafety Commissioner, Office of the eSafety Commissioner
- Privacy Commissioner Carly Kind, Office of the Australian Information Commissioner Moderator:
- Lorraine Finlay, Human Rights Commissioner, Australian Human Rights Commission Format: Commissioners will speak to the challenges presented by neurotechnology in their field for 10 minutes each. This will allow 15 minutes for moderated questions.



# Possible Questions for speakers Age Discrimination Commissioner

- What are the major opportunities and challenges that neurotechnologies pose to the rights of older persons? (i.e. could advance autonomy, could give rise to discrimination in access to technologies etc.)
- How can we ensure older persons' inclusion and nondiscrimination in the context of neurotechnologies? (i.e. adequate legal protections, education and awareness etc.)
- How can we strengthen protections for the rights of older persons seeking to, or already using neurotechnologies? (i.e. would a convention on the rights of older people help).

# eSafety Commissioner:

- What are the major opportunities and challenges that neurotechnologies pose to online safety?
- How can we protect children and young people from the risks presented by neurotechnologies? How can this be balanced against ensuring children and young peoples' agency?
- How can we ensure responsible innovation in the context of neurotechnologies? (i.e. safety by design?)

# **Privacy Commissioner:**

- What do you think are the major opportunities and challenges that neurotechnologies present to privacy? (i.e. protecting 'mental privacy', obtaining genuine and informed consent, the appropriate collection/use/ distribution/storage of neural data etc.)
- Do you think Australia's privacy laws are equipped to adequately protect individuals' privacy, including safeguarding neural data and related information?
- Privacy law reform has already been signalled for later this year. Is
  it likely that reforms will improve Australia's preparedness to
  protect privacy in the context of neurotechnologies (i.e. expanding
  data subject rights)?

# Event agenda

9:45 AM - 10:00 AM Doors Open

OAIC

10:00 AM - 10:10 AM Welcome and Acknowledgement of Country

s22

10:10 AM - 10:25 AM Introduction to the Symposium - Lorraine Finlay

10:25 AM - 10:40 AM The Cochlear Implant - Greg Watkins, Cochlear Ltd

10:40 AM - 10:55 AM Brain Mapping - Stephane Doyen, Omniscient Technology

10:55 AM - 11:15 AM Morning Tea

11:15 AM - 12:00 PM Regulatory Horizons – Considering Tomorrow's

Challenges, Today - Commissioner Panel

12:00 PM - 1:00 PM Lunch

# Logistics and other information

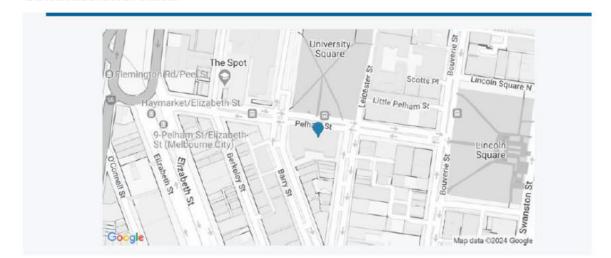
# **Event details**

When: Tuesday 18 June 2024, 1115 am - 1200 AEST.

**Commissioner Kind:** Please arrive at address by **10:30 at** Room 202/203, University of Melbourne Law School, 185 Pelham Street, Carlton VIC.

# **Arrival information:**

s47F will be there to meet Commissioner Kind.



# Other speakers

Robert Fitzgerald, Age Discrimination Commissioner Bio: AHRC website



Julie Inman Grant, eSafety Commissioner Bio: <u>eSafety website</u>



Moderator: Lorraine Finlay, Australian

**Human Rights Commissioner** 

Bio: Australian Human Rights Commission

website, LinkedIn



# Attachment B: Talking points, key facts and positions

Presentation by Australian Privacy Commissioner Carly Kind

**Good morning** 

 Thank you to AHRC for this opportunity and their paper, fascinating to me as an SF fan (thought crimes, Minority Report?),



- my human rights approach to privacy and the notion of cognitive liberty
- What don't we know? Neural technology is not mentioned in Privacy Act nor its review, nor in GDPR. Discussion where it fits within concept of sensitive information. The right to mental privacy.
- 3. Regulatory developments overseas
- 4. Discussion of consent how do you know how to give informed consent when you don't know what is being collected about you? How do you correct information when you are not sure what is collected or how it has been collected.
- 5. The privacy risks of neurotechnologies:
  - a. Targeted marketing
  - b. Bias in assessment (as per facial recognition)
  - c. Workplace surveillance monitoring
  - d. Sensitive health information collected risk of hacking of devices – as well as ability to determine sexual orientation, religious beliefs etc
- Our work with DP-Reg on artificial intelligence, what that has found and potential lessons. Refer also our work in biometrics and facial recognition
- 7. Absolutely underlines the importance of Privacy by Design and PIAs, and a precautionary approach
- 8. How the Privacy Act review will help us deal with this the importance of the positive obligation for fair and reasonable handling of PI.

9.	Summarise, the basics still apply, take a steady approach, working
	co-operatively.



# Questions

# **Privacy Commissioner:**

- What do you think are the major opportunities and challenges that neurotechnologies present to privacy? (i.e. protecting 'mental privacy', obtaining genuine and informed consent, the appropriate collection/use/ distribution/storage of neural data etc.)
- Do you think Australia's privacy laws are equipped to adequately protect individuals' privacy, including safeguarding neural data and related information?
- Privacy law reform has already been signalled for later this year. Is
  it likely that reforms will improve Australia's preparedness to
  protect privacy in the context of neurotechnologies (i.e. expanding
  data subject rights)?

Attachment C: Background

# PRIVACY AND THE RISE OF "NEURORIGHTS" IN LATIN AMERICA

# **BETH DO**

Christopher Wolf Diversity Law Fellow

**ABOUT BETH** 

**BLOGS BY BETH** 

# JAMESON SPIVACK

Senior Policy Analyst for Immersive Technologies

ABOUT JAMESON SPIVACK

**BLOGS BY JAMESON SPIVACK** 

# MARIA BADILLO

Policy Counsel for Global Privacy

ABOUT MARIA

BLOGS BY MARIA

Authors: Beth Do, Maria Badillo, Randy Cantz, Jameson Spivack

"Neurorights," a set of proposed rights that specifically protect mental freedom and privacy, have captured the interest of many governments, scholars, and advocates. Nowhere is that more apparent than in Latin America, where several countries are actively seeking to enshrine these rights in law, and some even in their Constitutions.

The rapid global <u>proliferation</u> of **neurotechnology**—devices that can access mental states by decoding and modulating neural activity—has generated a large amount of consumer **neurodata** (also known as neural, brain, or cerebral data; brain information; mental activity; etc.). As most existing privacy laws do not separately or explicitly regulate neurodata—even though such data is normally covered by the broad definitions of "personal data" in such legislation—several governments and international bodies have begun to develop specific legal protections for this type of personal data.

This analysis focuses on current legislative efforts in Chile, Mexico, and Brazil, which are indicative of how far the conversation in Latin America has progressed. Other jurisdictions, such as the <u>United States</u>, <u>Israel</u>, <u>South Korea</u>, and <u>Europe</u>, are also in the nascent stages of discussing protections for mental privacy. As neurotechnologies continue to evolve, industry and regulatory bodies alike should look to Latin America for developing trends and best practices.

# 1. What is neurotechnology?

Neurotechnology is an umbrella term for technologies that allow access to neurodata. Raw neurodata is collected from an individual's central nervous system (the brain and spinal cord) and/or peripheral nervous system (the nerves outside the brain and spinal cord), including electrical activity between these systems. Neurotechnology includes both traditional techniques such as electroencephalography (EEG) testing and magnetic resonance imaging (MRI) scans, as well as new methods that can monitor or modulate brain activity.

Neurodata is valuable and uniquely sensitive as it can access a person's emotions, biases, and memories. For example, EEGs can measure inattention, as brainwaves can indicate whether someone's mind is focused or wandering.

With sufficient data over a period of time, brainwave patterns may also even be more uniquely identifying than <u>fingerprints</u>.

# 2. What are neurorights?

"Neurorights" have been formulated to encompass mental privacy, integrity, and liberty. They are not yet widely recognized at the national level or codified in an international human rights framework, and there is disagreement about their usefulness as a conceptual framework. Some prefer using other terms such as "mental privacy" or "cognitive liberty;" others question the necessity of introducing new rights, or if current legal frameworks are sufficient or could be strengthened to account for them. Neurorights can be simplified into five fundamental rights:

- Mental Privacy: Personal neurodata should be private, and should not be stored or sold without consent.
- Personal Identity: Neurotechnology should not alter "mental integrity," or an individual's sense of self.
- Free Will: Individuals should retain decision-making control, without unknown manipulation via neurotechnology.
- Fair Access to Mental Augmentation: Cognitive enhancement neurotechnology should be accessible to everyone.
- Protection from Bias: Neurotechnology algorithms should not discriminate.

# 3. The emergence of neurorights

Advances in neurotechnology, partly funded by large research programs such as the US-based Brain Research Through Advancing Innovative Neurotechnologies (BRAIN) Initiative, have spurred global interest in establishing legal safeguards for the brain and neurodata. In 2019, the Organisation for Economic Co-operation and Development (OECD) developed the first international standards to respond to neurotechnology's ethical, legal, and social challenges. The OECD's Recommendation on Responsible Innovation in Neurotechnology provides guiding principles to prioritize safety, inclusivity, collaboration, and trust in neurotechnology. In 2022, the UNESCO International Bioethics Committee issued a report on the ethical issues of neurotechnology and advocated for a comprehensive governance framework.

On a regional level, the Inter-American Juridical Committee of the Organization of American States (OAS) issued a <u>Declaration</u> on neuroscience and neurotechnologies and human rights in 2021. Two years later, the OAS followed up with a set of <u>Principles</u> to align international standards to national frameworks. In the same year, the Ibero-American Network of Data Protection Authorities (RIPD), the main forum for Spanish- and Portuguese-speaking data protection regulators, declared <u>support</u> for the OAS Declaration and Principles and announced the establishment of a working group on neurodata.

Perhaps the most consequential call for action was the 2022 <u>Neurorights Model</u> <u>Law</u>, drafted by the Latin American and Caribbean Parliament (Parlatino), a

regional organization that promotes regional integration through legislative harmonization. The model law provides both structure and foundational concepts to regulate neurotechnology, including establishing an independent oversight authority and providing redress mechanisms.

Transnational stakeholders such as the OAS and Parlatino have played large roles in establishing Latin America as a leading player in the neurorights discussion. However, legislative initiatives at the domestic level may prove more influential, as their impact continues to reverberate in Latin America and beyond.

# 4. Chile: The first country to protect "mental integrity" in its Constitution

As a pioneer in the neuroprivacy movement, Chile was the first country to <u>amend its Constitution</u> to protect "mental integrity" and neurodata in 2021. Specifically, the provision states that "the law shall regulate the requirements, conditions, and restrictions for [neurodata], and shall especially protect brain activity, as well as the information derived from it." Furthermore, scientific and technological developments are to be conducted with "respect for [...] physical and mental integrity."

Led by Senator Guido Girardi Lavín and several other legislators, the amendment centered on the individual identity as an intrinsic value of human evolution and referred to physical and psychic integrity as its main elements. The legislators asserted that any technological development affecting mental integrity, as a fundamental right, should be authorized by law. Simultaneously, the same legislators introduced <a href="Bill 13.828-19">Bill 13.828-19</a>, which aimed to further regulate neurotechnology by requiring consent to use neurotechnology and establishing penalties for noncompliance.

In 2023, only two years after the country's Constitution was amended, Chile's Supreme Court became the first court to rule on a <u>neuroprivacy case</u>. The plaintiff, Senator Girardi, alleged that his brain data was insufficiently protected by the US-based Emotiv's "Insight" device, a headband that records detailed information about the brain's electrical activity. The Court ultimately found that Emotiv violated Sen. Girardi's constitutional rights to physical and psychological integrity as well as the right to privacy, setting aside Emotiv's arguments that the harms were hypothetical. Citing both Chilean domestic law and international human rights law, the Court focused on the fact that Emotiv retained Sen. Girardi's data for research purposes, even in anonymized form, without obtaining prior consent for this specific purpose. In addition to setting a precedent for neuroprivacy litigation, this case reflects the neurorights movement's influence beyond the policy sphere.

# 5. Mexico: Proposed constitutional amendment for neuroprivacy rights

As of March 2024, there are two pending neuroprivacy bills that seek to amend Mexico's Constitution. The <u>first bill</u>, proposed by Deputy María Eugenia Hernández Pérez, would include the right to individual identity, as well as physical and psychological integrity. The Chilean constitutional amendment's

influence is noticeable throughout the Mexican bill, including language requiring the State to respect mental privacy and integrity. Moreover, the proposal has the same wording as Chile's constitutional amendment and similarly spotlights the value of individual identity.

The proposal centers on human identity and its relation to technology, and not solely privacy and data protection, which are already recognized as two separate fundamental rights under <a href="Article 16">Article 16</a> of <a href="Mexico">Mexico</a>'s Constitution</a>. It includes broad legal safeguards to ensure the confidentiality of neurodata collection, informed consent before access, clear limits on neurotechnologies, and anti-discrimination measures. Moreover, the bill notes that while some local laws protect human rights and neurodata in the context of medical and scientific uses, there is a lack of regulation for non-medical uses.

The <u>second Mexican bill</u>, spearheaded by Senator Alejandra Lagunes Soto Ruiz, would amend Article 73 of the Constitution to provide congressional authorization to pass federal legislation related to artificial intelligence (AI), cybersecurity, and neurorights. Under this authority, Congress could safeguard mental privacy, cognitive autonomy, informed consent for the use of brain data, identity and self-expression, non-discrimination, and equal access to technology.

Both bills acknowledge that neuroprivacy is an emerging concept and focus on how neurotechnology could jeopardize fundamental rights. Although these bills approach the issue from different viewpoints, they both seek to protect personal data and build citizen trust. Additionally, in November 2023 the Mexican Data Protection Authority published a Digital Human Rights <u>Charter</u> that recognizes the five fundamental neurorights.

# 6. Brazil: Proposed constitutional amendment and neuroprivacy rights in privacy law

Several neuroprivacy initiatives have gained traction in Brazil. <u>Bill 29/2023</u>, introduced by Senator Randolph Frederich Rodrigues Alves in June 2023, seeks to amend the Brazilian Constitution to include protections for mental integrity and algorithmic transparency. In particular, the <u>proposal</u> highlights that recognizing "mental integrity" is essential to expand the "legal and normative understanding of human dignity in this new digital context" that protects both personal data and the "psychic and physical integrity of human beings." The proposal was presented to the Senate in June 2023 and is pending until a <u>Rapporteur</u> is appointed to review the bill. <sup>1</sup> Of note, the Brazilian Constitution was amended in February 2022 to include a right to the protection of personal data, distinct from the right to privacy.

Separately, <u>Bill 522/2022</u>, introduced by Deputy Carlos Henrique Gaguim in March 2022, would amend Brazil's General Data Protection Law (LGPD) to regulate neurodata as a category of sensitive data. The bill would add a new section to regulate the processing of neurodata, emphasizing that the request for consent must "clearly and prominently indicate the possible physical, cognitive and emotional effects" of processing neurodata. Currently, Article 5 of the LGPD establishes racial and ethnic origin; religious, political, and philosophical affiliations; health, sexual and life data; and genetic and biometric

data as categories of sensitive data. However, the <u>proposal</u> highlights the need to include neurodata as a distinct category of sensitive data, not to be confused or associated with biometric data. The bill was approved by the Health Commission Rapporteur in October 2023 and awaits further consideration.

The neurorights discussion has also made its way into Brazil's Federal Civil Code. In December 2023, the Sub-Committee on Digital Law of the Commission of Jurists, who are responsible for reviewing the Civil Code, submitted a <u>report</u> that seeks to recognize neuroprivacy under the LGPD. Independently, in December 2023, <u>Río Grande do Sul</u>, Brazil's fifth-largest state by population, amended its Constitution to include neurorights, specifying mental integrity as a constitutional principle.

# 7. Other regional initiatives

Similar legislative efforts are underway in the region, with some variations:

- Costa Rica proposed <u>amending</u> the country's data protection law to include a definition of biometric data which, in contrast to Brazil's proposal, categorizes neurodata as biometric data.
- Colombia is considering <u>updating</u> its data protection law to include a section specific to the processing of data through Al and neurotechnologies. The proposal sets out specific obligations for accessing and processing neurodata.
- Argentina has two pending bills: <u>Bill 2446/23</u> proposed the creation of a bicameral committee to develop a neurorights framework. Separately, another <u>bill</u> would amend the Federal Code of Civil Procedure to allow neurotechnologies that infer mental activity as admissible evidence.
- Uruguay's Parliament reported that elected officials have met with their Chilean counterparts to <u>discuss</u> neurorights. In February 2024, Deputy Rodrigo Goñi <u>indicated</u> that Parliament is considering regulating neurotechnologies and providing safeguards for brain integrity and neurodata.

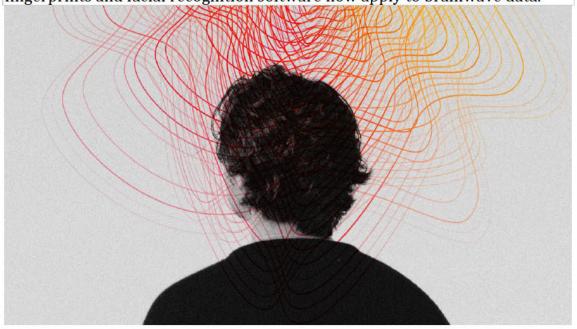
As neurotechnology continues to advance, it raises key questions about how the data involved should be regulated. Latin America is at the forefront of that conversation and has paved the way in recognizing neuroprivacy, from Chile's Constitution, to Mexico and Brazil's pending legislation. Regional frameworks, such as the OAS Declaration and Principles, illustrate that neurorights are coalescing on the international level as well. The groundswell of legislative proposals and domestic laws demonstrates that the fight for neuroprivacy is here to stay—and for now, at least, Latin America is the place to watch.

<sup>1</sup> According to the Brazilian Chamber of Deputies <u>Internal Rules</u>, <u>Art. 56</u>, committee bills and other proposals will be examined by a Rapporteur who must issue an opinion.

# **FAST COMPANY**

# What Colorado's new law means for brain-wave privacy in the Neuralink era

Under the legislation, the same privacy measures that are extended to fingerprints and facial recognition software now apply to brainwave data.



[Images: zaie/Adobe Stock; Blake Cheek/Unsplash]

# BY <u>ELLIE STEVENS</u>3 MINUTE READ

Lawmakers have long grappled with data privacy as it pertains to our devices and vehicles. But there's a new battleground emerging in the privacy battles: our brains.

Governor Jared Polis signed a bill that protects brain waves as "sensitive information" under the Colorado Privacy Act. Under the law, the same privacy measures that are extended to fingerprints and facial

recognition software now apply to brainwave data. The law comes on the heels of the release of neurotechnologies such as <a href="Elon Musk's">Elon Musk's</a>
<a href="Neuralink">Neuralink</a>, a brain implant that has the ability to translate thought into action, and which could, its supporters argue, help develop <a href="treatments">treatments</a>
<a href="formental diseases and improve people's focus">focus</a>.

The bill states that these technologies "raise particularly pressing privacy concerns given their ability to monitor, decode, and manipulate brain activity," noting that these technologies cause an involuntary disclosure of information.

# WHY NOW?

Neurotechnology remains one of the buzziest technologies around, with the market reaching a \$13.47 billion valuation in 2023 and is projected to grow to \$15.28 billion in 2024, according to a Yahoo Finance report.

Industry growth brought a shift in the use case for this technology, which the law cited as a reason for urgency. While this technology was previously confined to labs and focused on research and rehabilitation, it's creeping toward adoption in sectors ranging from therapy to trucking. As the technology scales, supporters of the Colorado law hope to see more states opt for privacy protection. The Colorado law states that when noninvasive neurotechnology is used outside of a medical context, it is considered a consumer product and operates without regulation or data protection standards. A number of states are following Colorado's lead, with California and Minnesota already working to pass legislation to protect neural data.

# NEUROTECHNOLOGIES' CAPABILITIES AND CONCERNS

According to the NeuroRights Foundation, a New York-based advocacy group, neurotechnologies put at risk our rights to personal identity, free will, mental privacy, equal access to mental augmentation, and protection from algorithmic bias. More specifically, commercial neurotechnology's writing and reading capabilities should give us the most cause for concern, says Eran Klein, an associate professor of neurology at Oregon Health and Sciences University.

Writing technologies, which cause the brain to perform specific tasks by stimulating its electrodes, can be used to treat diseases like ALS and Parkinson's. But they also could be used to change a person's

actions, or to alter a person's identity by changing their desires or feelings, Klein says.

On the reading front, neurotechnologies can be used to infer messages about what a person is thinking or feeling, regardless of whether the person wants those thoughts made public, Klein says. The technology can also be used for mental augmentation, which some say will further issues of inequity.

"There is a fine line between treating diseases and enhancing people's abilities that already fall within a normal range," Klein says.

As this neural data now falls under the Colorado Privacy Act, consumers can access, correct, and delete their data, and companies are subject to disclosure policies and data regulations.

# DOESN'T SOCIAL MEDIA TRACK ME ALREADY?

While many researchers are thrilled with the new legislation, some have taken issue with its narrow focus.

"We forget there is already sensitive personal information at risk," says Laura Cabrera, the chair in neuroethics at Pennsylvania State University. "The focus on neurodata is a missed opportunity [to combat other privacy risks]."

Cabrera doesn't see much of a difference between neurotechnology's potential capabilities and the very real actions taken today by internet and social media companies. "Mind control is already here," she says. "Think about how much social media controls our actions."

Supporters of the law, on the other hand, assert that the rapid expansion and capabilities of neurotechnology warrant this sense of urgency. "The Colorado bill is historic," says NeuroRights cofounder and chair Rafael Yuste. "It's the first time that neural data is legally defined and protected."

# THE GUARDIAN

Interview

# Prof Nita Farahany: 'We need a new human right to cognitive liberty'

# Zoë Corbyn

The author of The Battle for Your Brain has serious reservations about neurotechnology, from the surveillance of mental experiences to 'brainjacking'

Sun 5 Mar 2023 01.00 AEDT

Our brainwave activity can be monitored and modified by neurotechnology. Devices with electrodes placed on the head can record neural signals from the brain and apply low electric current to modulate them. These "wearables" are finding traction not only with consumers who want to track and improve their mental wellness but with companies, governments and militaries for all sorts of other uses. Meanwhile, firms such as Elon Musk's Neuralink are working on next-generation brain implants that could do the same thing, only with far greater power. While the initial use may be to help people with paralysis to type, the grand idea is for augmentation to be available to all. Nita Farahany, a professor of law and philosophy at Duke University who studies the ethical, legal and social ramifications of emerging technologies, is sounding the alarm.

Technology that can read our minds sounds terrifying. But it is also way ahead of where things are. Aren't you jumping the gun? I don't think so and, furthermore, we dismiss it at our peril. While the technology can't literally read our complex thoughts, there are at least some parts of our brain activity that can be decoded. There have been big improvements in the electrodes and in training algorithms to find associations using large datasets and AI. More can be done than people think. There are a lot of real-world applications and major tech companies like Meta are investing in it.

# What's the danger?

There are profound risks from both the commodification of the data but also what it means to have your brain activity monitored by others and what that does to freedom of thought. The technology is at an inflection point: use is ascending steeply but it is not yet mainstream. We have a moment, before the terms of service are set by others, where we can have a voice in how it is used and deployed in society.

# What uses most worry you?

Applications around workplace brain surveillance and use of the technology by authoritarian governments including as an interrogation

tool I find particularly provocative and chilling. We do see the technology starting to be used in some ways that are more like involuntary neural surveillance.

I suspect we will come to forget that the earbuds we are using to make a conference call can also track brainwave activity

# What should we set in place to protect ourselves?

To start we need a new human right to "cognitive liberty", which would come with an update to other existing human rights to privacy, freedom of thought and self-determination. All told it would protect our freedom of thought and rumination, mental privacy, and self-determination over our brains and mental experiences. It would change the default rules so we have rights around the commodification of our brain data. It would give people control over their own mental experiences and protect them against misuse of their brain activity by corporate and government actors, weighed against societal interests.

Plenty of technology to digitally monitor workers is <u>already in use</u>. What extra could employers get from monitoring brain activity? And wouldn't it be a bit cumbersome to wear at work?

The extra is what is hidden inside your brain that wasn't expressed in your email and wasn't on your computer screen. It includes things like your level of fatigue, engagement, focus, boredom, frustration and stress — metrics that purportedly can be measured with high accuracy.

The form was weird headbands a decade ago but now we're talking about the same devices that you're using already in the workplace – headphones and earbuds – simply also having brain sensors. I suspect we will quickly come to forget that the same earbuds that we are using to make a conference call can also track brainwave activity, just in the same way we forget our phones are tracking everything about us.

One touted use is criminal justice. The US firm Brainwave Science sells so-called "brain fingerprinting" technology it says will "transform your interrogations". The company claims to have numerous international government security agencies as customers. We have a societal interest in catching criminals...

The US criminal justice system, as far as we are aware, does not use these techniques and, if it did, criminal defendants would need to submit to it voluntarily. But whether other parts of the US government are using it is unclear. The use is troubling, and I don't think it is justified. There is scepticism about the scientific validity and we have also almost always relied on the need for investigators to gather and develop a case against an individual without going to the criminal themselves because of the abuse that can happen.

# How concerned are you about the military applications of neurotechnology – so called "brain control" weaponry?

Deeply concerned and particularly so when it comes to authoritarian regimes like China, who could prevent or quell demonstrations in ways that are powerful and sinister. The Biden administration has sanctioned Chinese research institutes and firms for their purported investment in brain-controlled weapons. Potential possibilities with this type of weaponry include mental manipulation of individuals to shape their thinking, brain control interfaces where weapons can be controlled with the power of thought and microwave weapons that might be used to mentally disorient large numbers of people. International action against the development and use of this type of weaponry would help.

# Would you ever consider a brain implant?

Based on today's technology, no way. None of it is safe or effective for healthy individuals. But, in time, maybe. Needed would be an acceptable safety profile, applications that would make me interested and really strong rights to give me confidence my data and access to my brain wouldn't be misused.

# What applications might be compelling? A big reason why muchhyped Google Glass was ultimately rejected was because it didn't have any...

The idea of a more seamless brain-to-technology interaction could be compelling for some people. In the same way you use a mouse and a keyboard, you could just use your brain. You could turn on the lights or adjust the thermostat just by thinking about it.

Probably more compelling would be the ability to communicate brain to brain with another person. If I could transfer you a full resolution thought or share with you a memory in my brain – the sight, the smell, my feelings – it would be transformational for how we communicate and empathetically relate to one another.

# Is there a risk of brain implants being hacked?

It's a terrifying possibility. And I worry not just about somebody monitoring your thoughts, but also manipulating them or trying to instil new thoughts and experiences. If "brainjacking" did occur, it could kill the tech: people might decide that the risks are too profound to use it. Or maybe it won't bother us so much: we take so little care in protecting our online privacy, even when we claim to want it.

 The Battle for Your Brain by Nita Farahany is published by St Martin's Press on 14 March (£25.99)

OAIC

# Summary - AHRC - Peace of Mind - Neurotechnology Paper

# Report findings and key recommendations

Report released by the Australian Human Rights Commission (AHRC) in October 2025, following a 2 year project on neurotechnology and human rights.

The report discusses the areas of rights protection which are currently most relevant to neurotechnology, and notes that further discussions of human rights implications will need to occur as neurotechnology develops.

# **Broad argument:**

 Neurotechnology is rapidly developing and has huge potential, but also presents significant and complex risks to human rights. Robust safeguards must be introduced as, not after, neurotechnology develops, to ensure that unintended harms do not occur and organisations progressing the benefits of neurotechnology do not lose track of the broader impacts.

# **Privacy Specific Arguments:**

- Neurotechnology exacerbates the privacy implications of technology as it challenges previous distinctions between private and public information – internal thoughts were previously impossible to measure, and thus by default private.
- There are a variety of concerning implications of under-regulated use of neural data, such as the tracking of individual's actions, emotions, and attitudes for the purposes of targeted nudging, political advertising, and discrimination.
- Only a fraction of the reforms to the privacy act committed to by the government have been implemented. The AHRC argues that the delivery of the remaining reforms is needed to ensure both that privacy laws in Australia are fit for the digital age and that neural data is protected. The AHRC recommends the government set out clear timelines for when each agreed amendment will be introduced.
- Highlights the limitations of the consent model of privacy which places the onus on individuals to be responsible for their data. Ensuring informed choice is particularly important if individuals are forced to choose between accessing the benefits of a technology at the cost of their neural data privacy, or not using the technology at all. The AHRC recommends that Neurotechnology companies create plain-English privacy policies and collection notices. The AHRC also highlights the potential of legislating a fair and reasonable test for collection, use and disclosure of personal information as agreed in principle by the government.
- Highlights ambiguity over whether different kinds of neural data are personal or sensitive information under the privacy act. The AHRC recommends that the

- government resource the **AHRC** and **OAIC** to produce guidance on the treatment of neural data and neurotechnology under the privacy act.
- Supports expanding the requirement to conduct a Privacy Impact Assessment for high-risk practices to the private sector, and for Neurotechnology to be explicitly identified as a high-risk practice. Supports neurotechnology companies conducting more holistic human rights impact assessments, which would capture privacy risks in addition to broader human rights concerns.

# Other high-level takeaways and recommendations:

- Freedom of expression: Neurotechnology can have beneficial impacts on people's rights to self-expression and access to information by allowing them to express themselves through an implant when diseases like MND or ALS impact their ability to communicate.
- Freedom of thought: Neurotechnology poses a fundamental challenge to the right of freedom of thought, as it can be used to decode, modify and manipulate an individual's internal reactions. The AHRC recommends that the UN Human Rights Committee provide guidance on freedom of thought and neurotechnologies, and that the Australian Government legislate to prohibit the use of neuromarketing for political advertising, polling research, and other consumer purposes.
- **Criminal justice implications:** Use of Neurotechnology in the justice system poses significant risks to human rights. The AHRC recommends that there be a moratorium on the use of neurotech in the justice system until the Australian Law Reform Commission has concluded an inquiry into in which circumstances (if any) it can be appropriately used.
- Consumer Rights: As neurotechnology has a high degree of technical complexity and risk, the AHRC recommends that a specialist consumer-oriented regulatory agency should be established to establish safety standards and regulate businesses engaging with neurotechnology.
- **Employment:** The AHRC recommends the banning of workplace neurotechnology, other than for addressing the most serious work health and safety risks in high-risk industries, with employee and union consultation. It also recommends the priority implementation of the ALRC's recommendations that surveillance legislation be technology neutral and workplace surveillance laws be made uniform throughout Australia.
- Online safety: Notes the likelihood of neurotechnology reaching a large group of people by becoming integrated into the gaming, social media and other online industries. AHRC recommends that neurotechnology companies implement a safety by design approach when developing products and services.

- Military Applications: Notes that military applications of neurotechnology are already being explored. Notes that there are significant risks around soldiers ability to provide free and genuine consent (particularly to implants), and complex interactions between neurotechnology and AI in the context of monitoring compliance with the Geneva Conventions. The AHRC recommends that Article 36 reviews of military neurotechnology devices using AI be regularly conducted throughout their lifecycle and, subject to national security impacts, be publicly disclosed.
- Children: Notes positive use cases (such as cochlear implants and supporting education) and risks (such as neuromarketing to children and barriers to children consenting). The AHRC recommends that organisations using neurotechnology demonstrate how they have addressed the Convention on the Rights of the Child (CRC) requirement to ensure the best interests of the child and that the Australian Government conduct Child Rights Impact Assessments when legislating around children and neurotechnology.
- People with disability
- Older people

# **Background**

# About the consultation:

The AHRC heard from over 100 people as a part of its project through roundtables, consultations, interviews and feedback sessions. The report makes 18 recommendations to ensure that innovation does not come at the expense of human rights.

Report notes global initiatives into examining the human rights implications of neurotechnology by UN organisations and the OECD.

Privacy Commissioner Carly Kind presented at the *Neurotechnology and Human Rights: Opportunities, Challenges and the Pathway Forward Symposium* in June 2024 that formed part of the AHRC's consultation process.

# <u>Definition of neurotechnology:</u>

The report adopts UNESCO's definition of neurotechnology:

"... devices, systems, and procedures—encompassing both hardware and software—that directly measure, access, monitor, analyse, predict or modulate the nervous system to understand, influence, restore, or anticipate its structure, activity, function, (speech, motor). Neurotechnology combines elements of neuroscience, engineering, material science, and computing, among others.

Neurotechnology spans medical and non-medical applications and includes tools that measure, infer, and influence nervous system activity, whether through direct interaction with the nervous system (both invasive and non-invasive) or by interfacing it with devices and systems. Of note, both open-loop (e.g. fixed-parameter brain stimulation) and closed-loop systems (e.g. state dependent stimulation) introduce complex ethical issues."

A core feature of many pieces of neurotechnology is a Brain-Computer Interface (BCI), which connects an individual's brain to a computer or device external to the human body. There are two core breakdowns of BCI's: Implantable vs wearable/external, and transmitting neural data vs altering neural activity.

Examples of neurotechnology have existed for some time in the medical field. Established examples include:

- Deep brain stimulation to eliminate tremors associated with Parkinson's disease (implantable/altering)
- Cochlear implants used to mimic the functioning of the inner ear (implantable/altering)
- fMRI and EEG neuroimaging, which measure neural activity in the brain (external/transmitting)
- LifeBand, a fatigue-tracking headband which alerts the worker and manager when they become dangerously drowsy, in use by over 5,000 organisations (primarily in mining, construction, trucking and aviation).



# Protecting Cognition: Background Paper on Neurotechnology and Human Rights

Australian Human Rights Commission

[December 2023]

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Australian Human Rights Commission

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#### 1 Commissioner foreword

Neurotechnology poses profound benefits for both individuals and our society as a whole. From improving the quality of life for people with a disability, expanding the human mind and challenging what it means to be human - this unique technology is truly a modern marvel.

However, as with all new and emerging technologies, human rights must be a central consideration when developing and deploying neurotechnological products in the global market.

The <u>Australian Human Rights Commission</u> (Commission) is concerned that this rapidly evolving technology is not currently supported by adequate safeguards and regulation to protect people from harm.

Our research, which has been informed by consultations and feedback with stakeholders from across the world, indicates that business, civil society, regulators and academia share concerns about how this technology will interact with human rights. Accordingly, there are several fundamental human rights and freedoms which may be impacted by neurotechnology such as the right to privacy, equality and freedom of thought.

Due to the rapid expansion of investment in neurotechnologies and its novel application, the Commission has produced this background paper to inform all people about what neurotechnology is, how it may impact human rights and some of the key challenges raised by the technology. This background paper is intended to spark discourse and raise the profile of human rights and neurotechnology in Australia and overseas. It is by no means a comprehensive assessment of every and all challenge posed by neurotechnology.

I look forward to civil society, business, regulators, government and academia relying upon the Commission's expertise in human rights and technology when using this resource. I hope that it is informative piece which stimulates debates at a policy level to spurn further considerations.

Lorraine Finlay

**Human Rights Commissioner** 

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023

# 2 Executive summary

The rapid advancement of neurotechnology in recent years has created significant and new opportunities for collecting, maintaining and utilising brain data to understand and/or manipulate the human mind.¹ Such applications potentially have immense benefits for both individuals and the broader community. It is not uncommon to see articles about the profoundly positive impacts of the technology – such as people being able to walk again² or improving our understanding of how to treat chronic pain.³

However, neurotechnologies also raise profound human rights problems which may require the international community to rethink its very approach to modern human rights.

Brain implants are not a fundamentally new technology and have been used in medical procedures for some time. For example, deep brain stimulation has been eliminating tremors associated with Parkinson's via electrical impulses to the basal ganglia of the brain since 1997.<sup>4</sup>

However, as technologies improve, the potential application of neurotechnologies multiplies. This is especially so when BCIs are utilised in conjunction with artificial intelligence (AI), which is still new and largely untested.<sup>5</sup>

Neurotechnology, especially when used in conjunction with AI, challenges what it means to be human and draws into question the traditional boundaries placed around an individual's internal thoughts and processes. There is a growing body of literature and international policy which considers the need to ensure that the human rights framework protects the mind of the individual.

It is likely that neurotechnologies will only become more pervasive and embedded in the everyday lives of individuals over the coming decade. While it is important to harness the benefits of neurotechnologies, there must also be greater scrutiny of the ethical and legal implications of its development and deployment.

This background paper seeks to stimulate discussion and advance Australia's understanding of both neurotechnology and its human rights risks. It is by no means a comprehensive analysis of every issue associated with neurotechnology. It is intended to provide a high-level 'snapshot' of current issues and challenges which must be considered.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023

# 3 Chapter 1: Background and context

It is now more important than ever to discuss the challenges associated with neurotechnology as investment and interest in the field is accelerating. With one in eight people living with a neurological disorder,<sup>7</sup> it is unsurprising that from 2014 to 2021 there has been a 700% increase in neurotechnology investment globally.<sup>8</sup> The broad range of potential applications of neurotechnology increases its viability as an investment option.

The United Kingdom's (UK) Information Commissioner's Office (ICO) cites the Regulatory Horizons Council's prediction that the neurotechnology market could be valued at \$17.1 billion USD by 2026, with the largest segments being neuromodulation, neuroprosthesis and neurosensing.<sup>9</sup>

Many governments are also investing heavily in neurotechnologies as organisations race to innovate, scale and secure market share. The industry is greatly assisted by government initiatives such as the United States (US) government's BRAIN Initiative and the Human Brain Project by the European Union (EU), which will contribute \$6.6 billion USD and €1.19 billion respectively.¹⁰ Further:

- China will invest \$1 billion USD until 2030 in the China Brain Project<sup>11</sup>
- Japan will invest 40 billion JPY in its Brain Initiative<sup>12</sup>
- Canada invested 267 million CAD in the Canada Brain Research Fund in 2021<sup>13</sup>
- UK invested 98 million EUROS between 2011 and 2020.<sup>14</sup>

However, it is not just the international community that is delving into the neurotechnological industry. In 2016, the Australian Brain Alliance was established with the support of the Australian Academy of Science. From 2016 to 2020, Australia's public investment in neurotechnology totalled \$350 million USD. However, the Australian Academy of Science is currently advocating for an Australian Brain Initiative (comparable to other countries) with a proposal for \$500 million in funding across five years.

Additionally, Australia is host to one of the top five brain computer interface (BCI) companies by total investment. As of 2021, NeuroTech Analytics placed Synchron as the second largest by total investment at \$130 million USD – behind only Neuralink at \$363 million USD.<sup>18</sup>

Synchron is works working on implantable BCI devices and is an endovascular BCI leader. 9 Synchron is developing the 'Stentrode' which can be inserted into the brain via blood vessels and used for controlling computers and treating neurological disorders such as paralysis. 20

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 In July 2022, Synchron was the first to utilise an endovascular BCI approach in the US after successful implantation. This will have significant implications for the scalability of BCIs as this approach does not require open-brain surgery.<sup>21</sup>

However, there are also several other neurotechnology organisations in the country, with Australia being placed in the top 10 countries world-wide in terms of the number of neurotechnology organisations.<sup>22</sup>

Despite the success of Australia's neurotechnology industry and the current proposals to establish an Australian Brain Initiative, there has been no Australian institutional responses to the human rights implications of neurotechnologies.<sup>23</sup> This has led to direct criticism of Australia's responses to human rights and neurotechnology as being under-theorised and lacking a response from regulatory or human rights institutions.<sup>24</sup>

## 3.1 Definitions

## **Neurotechnologies**

This background paper adopts the following definition of neurotechnologies:

...those devices and procedures used to access, monitor, investigate, assess, manipulate and/or emulate the structure and function of the neural systems of natural persons.<sup>25</sup> They are meant to either record signals from the brain and 'translate' them into technical control commands, or to manipulate brain activity by applying electrical or optical stimuli.<sup>26</sup>

However, it is important to note that, broadly speaking, there are three central types of neurotechnology:

- Devices which monitor brain activity
- Devices which intervene in brain activity
- Devices which are a combination of the preceding two types.<sup>27</sup>

## **Brain-computer interfaces**

At the core of neurotechnologies are BCIs.<sup>28</sup> BCIs are devices which connect an individual's brain to a computer or device (e.g. a smartphone, computer etc) external to the human body. BCIs facilitate bi-directional communication between the brain and an external device – either transmitting brain data or possibly altering brain activity.<sup>29</sup> This can operate either by implantation inside of a person's skull or via a non-implantable wearable device.<sup>30</sup>

BCIs can either be implantable or non-implantable. A non-implantable BCI will generally sit on an individual's head – often in the form of wearable technology

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 such as helmets, glasses and wristbands. It is these less invasive wearable BCIs which currently dominate the consumer neurotechnology market.<sup>31</sup>

Such technology may assist people with expressive or communicative disabilities to better communicate by decoding images in a person's mind.<sup>32</sup> These devices have already been used to successfully share images and words between people in different rooms via non-implantable BCI devices – enabling individuals to effectively exchange thoughts.<sup>33</sup>

Some BCIs are implanted via surgery inside of a person's skull and placed directly on the surface of the brain.<sup>34</sup> These electrodes then send brain data to a computer for analysis and decoding. Implantable BCIs are not new and have been utilised in medicine for some time. For example, deep brain simulators have been used to assist people with Parkinson's disease to regain mobility.<sup>35</sup>

#### Metaverse

For the purposes of this background paper, the Commission draws upon the definition of the Metaverse as provided by the XR Safety Initiative:

The Metaverse is a network of interconnected virtual worlds with the following key characteristics: presence, persistence, immersion and interoperability. Metaverse is the next iteration of the internet enabled by several converging technologies such as Extended Reality (XR), Artificial Intelligence (AI), Decentralised Ledger Technologies (DLTs), neurotechnologies, optics, bio-sensing technologies, improved computer graphics, hardware, and network capabilities.

Metaverse has four main aspects; presence, persistence, immersion and interoperability. Presence is the feeling of being present or physically located within a digital environment. Through stimulating realistic sensory experiences and enabling participants to interact with objects and other participants, it creates a sense of immersion and engagement within the virtual world, as if participants were in the same physical space. The sense of presence is carried out through technologies such as virtual reality glasses.

Persistence refers to the ability of virtual objects, environments, and experiences to assist over time, even when participants are not actively interacting with them. It allows participants to make progress, own virtual property, and build ongoing relationships.

Immersion refers to the degree to which a participant is fully engaged and absorbed in a virtual environment, to the point where the individual may forget about their physical surroundings. A sense of immersion is created

**Protecting Cognition: Background Paper on Neurotechnology and Human Rights,** 02 July 2023 through technologies such as virtual reality (VR) headsets, haptic feedback devices, and 3D audio.

Interoperability refers to the ability of different virtual worlds and systems to communicate and interact with each other seamlessly, allowing individuals to move freely between different digital environments and experiences. It is essential for creating a cohesive and interconnected virtual world that allows individuals to seamlessly move between different experiences and platforms.<sup>36</sup>

## 3.2 Consultations

The positions presented in this background paper are those of the Commission, informed by the views and opinions expressed by participants throughout consultation processes run by the Commission in 2023.

These consultations processes were held with business, government, regulators, civil society and academia in both written and oral formats. Across 2023 [insert] participants gave feedback in discussions with the Commission while a further [insert] provided written input.

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# 4 Chapter 2: Introduction to neurotechnology

The rapid advancement of neuroscience and neurotechnology in recent years has created significant opportunities for collecting, maintaining and utilising brain data to understand and/or manipulate the human mind.<sup>37</sup> Such applications potentially have immense benefits for both individuals and the broader community. It is not uncommon to see articles about the profoundly positive impacts of the technology – such as people being able to walk again<sup>38</sup> or improving our understanding of how to treat chronic pain.<sup>39</sup>

However, neurotechnologies also raise profound human rights problems which may require Australia and the international community to rethink its very approach to modern human rights.

Brain implants are not a fundamentally new technology and have been used in medical procedures for some time. For example, deep brain stimulation has been eliminating tremors associated with Parkinson's via electric impulses to the basal ganglia of the brain since 1997.<sup>40</sup>

However, as technologies improve, the potential application of neurotechnologies multiplies. This is especially so when BCIs are utilised in conjunction with AI, which is still an emerging area.<sup>41</sup>

For example, a recent experiment has seen the integrated use of neurotechnology and large language models to translate brain activity into words.<sup>42</sup> In this experiment, AI was capable of translating private thoughts into readable language by analysing fMRI scans, which measure the flow of blood to different regions of the brain.<sup>43</sup>

Unlike past neurotechnologies which require implantation to allow paralysed people to write by thinking, this new language decoder did not require implantation. As part of this experiment, participants listened to a recording while undergoing fMRI scans. Researchers were interested in how closely the AI translation reflected the actual recording. While most of the words were out of place, the basic meaning of the passage was largely preserved. Effectively, the AI was paraphrasing.

The original transcript of the recording stated:

I got up from the air mattress and pressed my face against the glass of the bedroom window expecting to see eyes staring back at me but instead only finding darkness.<sup>44</sup>

The decoded brain activity produced:

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 I just continued to walk up to the window and open the glass I stood on my toes and peered out I didn't see anything and looked up again I saw nothing.<sup>45</sup>

However, it isn't just neurotechnology utilising AI which has received international attention:

- There have already been proof-of-concept studies demonstrating brainto-brain interaction facilitated by neurotechnology.<sup>46</sup>
- Scientists have recorded the neural activity of individuals watching movies, and using that neural activity, managed to play back hazy images of the movie using only the brain activity.<sup>47</sup>
- Human brains have been directly connected to cockroach brains. This
  allowed the human to control certain behaviours, such as steering their
  paths by thought alone.<sup>48</sup>
- Invasive BCIs can also be used to control the actions of laboratory animals such as mice. While a mouse was engaging in a task, such as eating food, a BCI recorded its brain data. That data was then used to reactivate and stimulate the same parts of the brain that were previously recorded. This forced the mouse to eat again – even if it did not want to eat.<sup>49</sup>
- Researchers have found ways to use BCIs to implant artificial memories or images into a mouse's brain – generating hallucinations and false memories of fear.<sup>50</sup>

These are just a few examples of the increasing sophistication of these technologies. However, these examples also demonstrate that neurotechnologies are replete with possible human rights violations.<sup>51</sup> For example, if mice can be controlled, could the technology be improved to manipulate human thoughts and actions?

The need to scrutinise the human rights risks of neurotechnology is of unprecedented importance. This is largely due to the technologies capacity to:

- Access mental states of a person
- Verify subjective reports on those mental states
- Verify subjective (or first-person) reports regarding the nature and content of those states
- Contest first-person authority regarding mental states by overriding such introspective reports
- Control decoded mental states by providing input behaviourally or through direct brain stimulation.<sup>52</sup>

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 Neurotechnology, especially when used in conjunction with AI, challenges what it means to be human and draws into question the traditional boundaries placed around an individual's internal thoughts and processes. There is a growing body of literature and international policy which considers the need to ensure that the human rights framework protects the mind of the individual.

It is likely that neurotechnologies will only become more pervasive and embedded in the everyday lives of individuals over the coming decade.<sup>53</sup> While it is important to harness the benefits of neurotechnologies, there must also be greater scrutiny of the ethical and legal implications of its development and deployment.

Government, academics, policymakers and civil society are starting to work towards protecting the human mind from the human rights risks. However, despite the significant discourse in this field there are divergent opinions.

## 4.1 Protecting the human mind

There are three broad approaches to protecting the human mind from the adverse impacts of neurotechnologies according to the relevant literature.

The first school of thought advances that novel human rights (also known as 'neurorights') specifically protecting the brain are necessary. Advocates claim that existing fundamental rights and freedoms are insufficient to protect against the misuse of neurotechnology. Those who advance neurorights rightly note that when traditional rights and freedoms were introduced, the ability to monitor and manipulate brain activity was science fiction, barely conceivable as being real. Accordingly, new rights are necessary to reflect the monumental shift in what it means to be human due to the impact of neurotechnologies.<sup>54</sup> The proposal of neurorights has generated lively debate as many question their necessity, effectiveness and if it might lead to 'rights inflation'.<sup>55</sup>

The second school of thought provides that adaptive interpretations and applications of existing rights and freedoms are required to protect the brain – but novel neurorights are not. Those proposing such an approach are generally in agreement with those of the prior position that existing rights and freedoms in their current form and application offer inadequate protection. However, these advocates believe it's better to update our interpretations of existing human rights and apply them to neurotechnologies. There are certainly existing rights which can be positioned to address neurotechnologies, with the right to privacy and the right to freedom of thought, the right to bodily integrity being clear examples.<sup>56</sup>

However, such an interpretive approach to extend existing rights and freedoms will require a conscious effort by policy makers across jurisdictions and may be

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 slow to advance – which risks protections being outpaced by the rate of technological advancement. There are a variety of opinions on which school of thought is preferred as demonstrated in the submissions provided to the United Nations Advisory Body to the Human Rights Council's <u>inquiry into neurotechnology and human rights</u>.

The final group considers that no novel rights or new interpretations are necessary to protect the human mind. This position is largely outdated and rarely raised.<sup>57</sup>

# 4.2 Neurorights

'Neurorights' is an umbrella term which encompasses novel rights which protect the human mind. St While it is possible that existing human rights may apply to neurotechnologies, advocates for neurorights highlight the heightened risk profile of the technology and question the sufficiency of existing rights. St

When genuinely considering if it is best to introduce novel neurorights or to adapt existing human rights, it is necessary to carefully consider which approach is most appropriate. One key risk of introducing new rights is that it may contribute to the phenomenon of 'rights inflation' which threatens diluting the core idea (and universal nature) of human rights.<sup>60</sup>

Broadly speaking, proponents of neurorights suggest that existing treaties do not offer the robust and comprehensive human rights protection that a neurotechnological world requires. Instead, they advocate that today's era calls for a novel protective framework of neurorights.<sup>61</sup>

Given the profound ways in which neurotechnology will change the way we live our lives and what it means to be human, there has been great attention paid to how the boundaries of the brain and mental lives of people can be protected.

The Universal Declaration of Human Rights (UDHR) has provided a set of agreed fundamental rights and freedoms to guide how all humans should treat others and be treated. Since its adoption in 1948, it was followed by binding international human rights instruments, such as the International Covenant on Civil and Political Rights (ICCPR), which has been adopted by 173 countries, covering 90% of the world's population.<sup>62</sup>

Since 1948, technology has redefined how humans live and interact with one another. While much of this usage has led to improvements in quality of life, its widespread adoption also brings significant challenges, including to human rights.

Neurotechnology poses an especially novel risk to human rights as it can leap the boundary between the external world and the internal human mind,

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 invading our private emotions, thoughts and memories. The brain is like no other organ – it is what makes us who we are as individual human beings. While neurotechnologies present boundless opportunities for scientific and medical breakthroughs, human rights must be protected as this technology poses unique risks by the way that it interacts with the human brain.

The real challenge of this technology will be how to create frameworks and guardrails to protect against human rights violations – responding to the current risks posed by the technology, and forward thinking and flexible enough to adapt as the technology improves.

Current literature focuses largely on the neurorights of mental integrity, mental privacy and cognitive liberty as partly protected by international instruments such as the:

- UDHR
- ICCPR
- American Convention on Human Rights (ACHR)
- European Convention on Human Rights (ECHR)
- Charter of Fundamental Rights of the European Union (CFR).63

This has been further built upon by projects to determine the prospective scope of establishing human rights in respect of thoughts, emotions, and other mental states, both now and in the future.<sup>64</sup> These projects have been initiated by organisations such as the:

- United Nations
- Inter-American Juridical Committee
- Committee on Bioethics of the Council of Europe
- United Nations Educational, Scientific and Cultural Organization (UNESCO)
- Organization for Economic Co-operation and Development (OECD).65

It is notable that there are established human rights which should be applicable to many uses of neurotechnology, such as the rights to:

- · Bodily integrity
- Privacy
- Personal identity
- Freedom of thought
- Autonomy.66

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 However advocates of neurorights argue that these rights are insufficient given the uniqueness of neurotechnologies. The significant attention currently being focused on neurotechnology and human rights is largely in response to the novel challenges the technology poses. For Allan McCay, an expert on neurotechnology and Deputy Director of the Sydney Institute of Criminology, poses just some of the legal and ethical questions that must be considered, asking:

what if a person commits a criminal act by using the implanted microchip. Who would be responsible for the criminal violation? So, if another person somehow manages to control the electronic device to commit a violation, how would the courts address the legal issues? In essence, how do we regulate human mental capacity?

There are other questions that can come up when implementing this technology. For example, could solicitors one day be instructed to use a microchip to enhance their mental capabilities? Could the courts force known offenders to use special microchips, so their brain activities are monitored and controlled by a government agency?<sup>68</sup>

There has been serious consideration of the application of neurotechnology in the criminal justice system. Academics have questioned if the police may deploy neurotechnology to analyse brain data and make inferences about suspects and witnesses (such as truthfulness) in their investigations. Some have gone further and raised concerns that neurotechnologies may be used in sentencing and post-imprisonment conduct:

for example, a closed-loop device could be used to monitor the brain of an offender and intervene upon it in order to avert an angry outburst that might precipitate an offense.<sup>69</sup>

As a result of these novel problems, there is global discussion of how to protect the human mind from neurotechnology:

- Chile has been working on introducing neurorights into its national legal system via reform to its constitution. Senator Girardi pointed to the failure to regulate social media and internet platforms in the past, to highlight why it is important to regulate technology before it becomes a problem.<sup>70</sup>
- Spain has included neurodata specific sections in its Digital Rights Charter.<sup>71</sup>
- The United Nations, Inter-American Juridical Committee and the Council
  of Europe are all exploring whether existing human rights and freedoms
  provide sufficient legal protection from neurotechnologies.<sup>72</sup>

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- UNESCO has published an initial <u>report</u> on the risks and challenges of neurotechnologies for human rights.<sup>73</sup> In 2023 it produced a follow up report.
- The UK ICO recently published a <u>paper</u> on neurotechnology.

Despite all of this movement on the global stage, there is no consensus on the correct approach. Even what supposed neurorights ought to look like is still contested as some call for specific neurorights to be created on an individual basis whereas others, such as Dr Nita Farahany, call for the introduction of cognitive liberty – which encompasses a bundle of rights. Regardless of the exact form of neurorights, the discourse often settles around the right to mental privacy, mental integrity and cognitive liberty.

## **Mental privacy**

Vint Cerf, Vice President and Chief Internet Evangelist at Google, once stated that 'privacy may actually be an anomaly'. A In a world of heightened data collection and surveillance, either by government or corporate entities, it seems possible that this statement will come true as brain data becomes the next piece of personal data to be harvested by organisations seeking to monetise it.

Mental privacy refers to the right to private thoughts, feelings, memories, emotions and brain data.

There is already significant commentary and calls for legislative reform about how to protect personal information online.<sup>75</sup> It seems like a natural progression for those discourses to now extend to the protection of brain data.

Brain data will likely give companies and governments the ability to make inferences about users of neurotechnologies. This can extend to their predisposition to neurological and psychiatric conditions or future behaviour. Such insights put those with access to the brain data in a powerful position to manipulate people either through direct intervention through neurotechnologies or by utilising the brain data to subversively push people towards certain decisions.

We already know that algorithms can make inferences about us, and suggest content we are most likely to engage with. While problematic, this issue is exacerbated where such tailored content or 'nudges' are made on the basis of brain data. Such breaches of mental privacy can result in manipulation or even physical harm to users.<sup>77</sup>

While there is no recognised express right to mental privacy, our feelings, thoughts and mental states may obtain implicit protection under the rights to:

Privacy

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- Freedom of thought
- · Freedom of expression.

## **Mental integrity**

Where the right to bodily integrity protects against interference with one's body, the right to mental integrity protects against interference with one's mind.<sup>78</sup> Sceptics argue that the mind is already protected by way of the brain being contained within the body, and propose that an additional protection for the mind would be superfluous.<sup>79</sup>

Such criticism ignores that with the advent of neurotechnology, interference with the mind may not interfere with the body. For example, non-implantable BCIs can interfere with brain activity and behaviour in intrusive ways, severely violating one's right mental integrity. However, because non-implantable BCIs are often wearable and non-intrusive, they may not violate the right to bodily integrity despite having serious impacts on a person's mind.<sup>80</sup>

While the right to bodily integrity may protect the mind from interference from some neurotechnology, it is unlikely it could extend to other forms of the technology such as non-implantable BCIs which are non-invasive in nature.

Unlike the right to mental privacy, the right to mental integrity has been recognised by various human rights instruments.

Article 17 of the Convention on the Rights of Persons with Disabilities (CRPD) states that:

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Further, article 5(1) of the ACHR states:

Every person has the right to have his physical, mental, and moral integrity respected.

## Article 8 of the ECHR states:

Everyone has the right to respect for his private and family life, his home and his correspondence.

There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 Jurisprudence of the European Court of Human Rights has recognised the right to mental integrity alongside the right to bodily integrity within article 8 of the FCHR 81

The Charter of Fundamental Rights of the European Union (CFR) article 3(1) states:

Everyone has the right to respect for his or her physical and mental integrity.<sup>82</sup>

Despite being recognised by multiple instruments, the exact scope of the right is unclear. However, the EU Network of Independent Experts on Fundamental Rights (set up by the European Commission) has determined that the right to mental integrity pursuant to article 3(1) CFR is a broad right.<sup>83</sup>

## Cognitive liberty?

While the right to mental privacy may better protect the inspection and access of the mind, the right to cognitive liberty seeks to protect mental states from influence and interference.<sup>84</sup>

Although the exact parameters of cognitive liberty are often contested, Bublitz claims the right comprises of two fundamental and interrelated principles:

- The right of individuals to freely use emerging neurotechnologies
- The protection of individuals from coercive or unconsented use of such technologies.85

Effectively the right to cognitive liberty contains both positive and negative freedoms. It contains a negative right to be free from external coercive control or interference – while also including a positive right to freely control one's own brain.<sup>86</sup>

Currently there are no express rights to cognitive liberty in human rights instruments or at law. However, it may receive some protection under the human right to:

- Freedom of thought
- Freedom of expression
- Self-determination.

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# 5 Chapter 3: Human rights impacted by neurotechnology

A key theme in the discourse on human rights and neurotechnology is whether it is better to understand human rights risks in respect of existing human rights (which may not be fit for purpose) or under new neurorights.<sup>87</sup> This background paper does not seek to provide a position on which approach is preferred, but rather to spark conversation on these competing approaches.

Regardless of which approach is preferable, it is important to highlight some of the existing human rights which will be impacted by neurotechnologies. Although there are a diversity of rights which will be impacted, for the purposes of promoting discourse at a high-level the background paper shall focus on just three; the right to privacy, freedom of thought, conscience and religion or belief and the right to equality and non-discrimination.

## 5.1 Right to privacy

The boundary between the external world and one's internal mental cognition has traditionally been an impenetrable one. Mental privacy is the last true bastion of protected information which is secret to ourselves. However, neurotechnologies challenge this notion. Unchallengeable statements about internal thoughts and feelings such as 'that's how I feel' can now be analysed, examined and tested.<sup>88</sup>

This ability to examine brain data and determine private thoughts, feelings and behaviours places human rights at risk. The right to privacy is a cornerstone human right. As noted by the Office of the Australian Information Commissioner (OAIC), it also underpins freedoms of association, thought and expression, as well as freedom from discrimination.<sup>89</sup>

The right to privacy developed over centuries. For example, in the fourth century BCE, Aristotle drew the distinction between the public sphere of politics and the private sphere of domestic life. Thousands of years later, the 'fourth industrial revolution' is characterised by rapid technological development. These changes have arguably reinforced the central importance of the right to privacy.

The right to privacy, in respect of neurotechnology, has become of such interest that even the UK ICO recently published its paper <u>ICO Tech Futures:</u> <u>Neurotechnology</u> on the risk to privacy.

It is due to the unprecedented ability to challenge internal thoughts that brain data is more sensitive and valuable than all other categories of personal data.<sup>90</sup> The collection of brain data will make it possible to track, analyse and predict the

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 actions and attitudes of individuals about anything from political leaning, sexual orientation or health status.<sup>91</sup> The risk to privacy is of the utmost concern in respect of brain data due to its implied use.

Neurotechnology products will record vast quantities and varieties of mental data which may be accessed without genuine consent. There are already issues about individuals 'giving away' their online personal data to third parties through collection notices.

The usage of such brain data could range from marketing companies using 'nudging' techniques to steer users towards certain products, employers seeking to monitor employee concentration in the workplace or even schools seeking to ensure children are paying attention and learning in class. The risks become more drastic when considering the usage of brain data by governments – especially those with poor human rights records.

It is possible that the decoding of brain data will one day be able to reveal information such as, for example, someone's sexual orientation, leading to possible discrimination and prejudicial treatment.<sup>93</sup> There has already been research claiming that computer-vision algorithms could predict sexuality from a single image of a person's face.<sup>94</sup> It is also possible that other personal information such as political affiliations or religious commitments could also be inferred from neurotechnologies in coordination with other technologies – however sexual orientation is used as an example of the risks below.

The 2020 update of the Global Legislation Overview of the State-Sponsored Homophobia Report concluded that there were 67 Member States with provisions criminalising consensual same-sex conduct, and six UN Member States that continue to impose the death penalty for consensual same-sex conduct. This is in addition to the many countries where individuals continue to face persecution and violence on a daily basis because of their sexual orientation or gender identity.

If mental privacy is not protected, the technology could lead to a widespread ability to identify, isolate and even kill people based on an assessment of their sexual orientation.

Even if such neurotechnologies are developed, the inaccuracy of such neurological tools does not reduce the risk of persecution and violence against individuals who might be targeted by this technology – whether on the basis of sexual orientation or other characteristics.

Although the collection, maintenance and usage of brain data raises ethical questions in isolation, the Commission has concerns about how this information will be used in tandem with other forms of personal data. For example, the gathering of seemingly small and innocuous pieces of personal data (browser

Commented [NL1]: OAIC note: We were unsure what the source of this statement is, but there are a range of issues in obtaining informed consent in the online environment where collection notices are opaque and/or complex.

It may be clearer to reframe this as follows: There have already been concerns raised about individuals providing their personal data online without a clear understanding of the way their information will be handled due to complex or opaque collection notices.

This framing sets out the link between complex or opaque collection notices and the issue of informed consent.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 history, biometric information etc) can, accumulatively, provide a detailed profile of an individual – dubbed the 'mosaic effect'.96

Many wearable devices, such as smart watches, now record bodily functions and are openly accepted by consumers. While this allows for the collection of information such as heart rate, geolocation and movement, with the inclusion of brain data, this will allow sensitive personal information to be extracted or inferred about a person on an unprecedented scale.<sup>97</sup>

#### Article 12 UDHR states:

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

### Similarly, article 17 ICCPR states:

No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

Everyone has the right to the protection of the law against such interference or attacks.

The right to privacy is also protected in many other international instruments.<sup>98</sup> The UN Human Rights Council also indicates that privacy is of increasing importance in a digital age where:

digital tools can be turned against them, exposing them to new forms of monitoring, profiling and control.99

Mental privacy will be of ever-increasing concern as neurotechnologies improve, and organisations and government are better able to commercialise the collection, maintenance and usage of brain data.

When considering brain data, a privacy model which places the onus on individuals to be responsible for the protection of their data, and to make informed decisions, is insufficient due to the heightened importance of that information.

The Commission's concern is predicated upon several matters:

- The 'privacy paradox'
- Lack of competition/alternatives which are more data secure
- The illusion of choice
- Power imbalances.

Commented [NL2]: OAIC note: Our understanding of the mosaic effect is that it refers to the accumulation of pieces of information that in isolation do not identify the individual or are of limited significance. We suggest removing the reference to biometric information which is often capable of identifying an individual and is a very sensitive data set.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 The 'privacy paradox' refers to the phenomenon that, despite understanding the privacy risks of a product or service, there is no obvious influence upon an individual's behaviour. Namely, individuals will still engage with privacy-adverse products and services even where they are highly aware of the risks. This does not mean that individuals do not care about their privacy.

For example a recent comprehensive survey conducted by the OAIC found that nine in 10 people have a clear understanding of why it is important to protect personal information.<sup>101</sup> Yet only 32% said they feel in control of their privacy, and half of those surveyed believe that if they want to use a service, they have no choice but to accept what the service does with their data.<sup>102</sup>

Furthermore, even where individuals do not genuinely understand how their data is being used, people will still disapprove of its misuse. Individuals have been shown to have a very strong negative reaction when confronted with the difference between:

- · How their data is actually being used and
- Their perception of how it is being used.<sup>103</sup>

This is particularly the case where the difference becomes explicit and too contrasting.<sup>104</sup> Many consumers willingly shared data on Facebook, however when the use of that data by Cambridge Analytica came to light, there was public outcry, with Facebook being required to appear at hearings before both the US congress and UK Parliament.<sup>105</sup>

Despite being aware of the risks, and disapproving of those risks to privacy, individuals are often unwilling, or unable, to stop using appliances or services which threaten their privacy.<sup>106</sup> This is especially so in respect of implantable BCIs which are invasive and difficult to remove – often requiring medical intervention, such as brain surgery.

This reluctance, or inability, to avoid products or services which threaten privacy may be partly in response to a lack of effective competition or alternative. The Australian Competition and Consumer Commission has previously found that a lack of competition and unavailability of reasonable alternatives (which may better protect privacy) can lead consumers to accept undesirable terms of use. <sup>107</sup> In addition, terms of use may be provided on a 'take-it-or-leave-it' basis across interrelated services which potentially leads to excessive data collection inconsistent with the wishes of the individual consumer. <sup>108</sup>

This affords individuals very little ability to 'choose' neurotechnology services and products which enable mental augmentation for consumer or medical reasons without risking privacy. It is also an unfair to ask someone with disability to 'choose' between their privacy and possibly lifechanging products.

Commented [NL3]: OAIC note: This data comes from the 2023 Australian Community Attitudes to Privacy Survey. We'd be grateful if you could cite it as the relevant source in the link and the footnotes?

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 The traditional model of privacy regulation places great emphasis on informed 'choice' as an effective safeguard for data and privacy. 109 However, the privacy paradox and numerous behavioural studies demonstrate that placing the onus on individuals to protect their own data is insufficient. 110

Such a model also does not acknowledge the substantial power difference between large companies and individual consumers – especially where mental augmentation will vastly improve quality of life for consumers or patients. Even where an individual understands how their data will be used, this power imbalance remains, as 'one party controls the design of applications and the other must operate within that design'.<sup>111</sup>

The privacy paradox, illusion of choice and power imbalances may all contribute to individuals being unable to utilise neurotechnology without relinquishing their privacy.

The Consumer Policy Research Centre in its <u>In whose interest? Why businesses</u> need to keep consumers safe and treat their data with care (Working Paper) put forward two alternative approaches to protecting data in Australia.

The Working Paper canvasses the creation of a duty of care or best-interest duty, which would operate similarly to fiduciary duties in the finance sector to hold businesses accountable for how they collect, share and use consumer data.<sup>112</sup>

The Working Paper also advocates for a:

Privacy Safety Regime which utilises concepts from product intervention powers and product safety interventions, proposing options that would allow governments and regulators to stop or limit obviously harmful uses of data as well as a process for regulators to proactively restrict and test new harmful practices as they evolve.<sup>113</sup>

## 5.2 Freedom of thought, conscience and religion or belief

Neurotechnology will potentially challenge what it means to have freedom of thought and agency over our own lives. As discussed above, BCIs can be used to override the thoughts and actions of laboratory mice. The application of neurotechnologies goes further and has the potential to decipher and alter perceptions, behaviours, emotions, cognition and memory – all fundamental aspects of what makes us who we are.<sup>114</sup>

This will allow the technology to one day manipulate people's beliefs, motivations and desires. This has led to disquiet about the possibility of unique forms of sophisticated 'mind control' – highlighting the need to better protect freedom of thought. As is rightly noted by UNESCO when discussing freedom of thought in this context:

Commented [eSafety4]: OAIC note: It may be helpful to highlight after this section that best interests considerations are included in some Privacy Act Review proposals to protect children, and that these are discussed further in section 7.1 (assuming you include these as per our later comments).

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 It is noteworthy that freedom of thought is not to be understood here merely in the traditional sense that people should be free to express their opinions or beliefs (forum externum), but in the literal sense of the freedom to think by themselves without being monitored by others (forum internum).<sup>116</sup>

Not all neurological manipulation will be negative, as patients experiencing treatment-resistant depression can now be treated using deep brain stimulation techniques (similarly to those used for Parkinson's disease). For example, treatment of this sort has led to severely depressed patients exhibiting a significant improvement in depression symptoms.<sup>117</sup>

While there is a well-articulated field of discourse on the freedom of thought, it is unclear if consideration has been given expressly to neurotechnology. 118

Article 18(1)-(2) ICCPR state:

Everyone shall have the right to freedom of thought, conscience and religion. This right shall include freedom to have or to adopt a religion or belief of his choice, and freedom, either individually or in community with others and in public or private, to manifest his religion or belief in worship, observance, practice and teaching.

No one shall be subject to coercion which would impair his freedom to have or to adopt a religion or belief of his choice.

Despite article 18(2) expressly stating that a person shall not be subject to coercion which impedes their ability to adopt a belief, there is no mention in the General Comment on Article 18 that would consider this in respect of neurological interference to coerce a decision – nor any mention of technological means of doing so.<sup>119</sup>

With an increasing understanding of the brain, it is possible that neurotechnologies in coordination with other technology (geotracking, data gathering etc) may be capable of not only coercing or manipulating a person's decisions but also discerning their internal thoughts or beliefs. It is concerning that, despite the protection in Article 18, this could lead to persecution based on a person's belief.

## 5.3 Right to equality and non-discrimination

In addition to the rights above, there is significant speculation on how neurotechnology may deepen social and economic divides in a way that violates the right to equality and non-discrimination.

Particularly, article 25 UDHR stipulates:

**Protecting Cognition: Background Paper on Neurotechnology and Human Rights,** 02 July 2023 everyone has the right to a standard of living adequate for the health and well-being of himself and of his family

#### Article 2 also states:

everyone is entitled to all the rights and freedoms ... without distinction of any kind such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

To prevent deepening inequality, the right to equal access to mental augmentation has been proposed by NeuroRights Foundation and the Neurotechnology Ethics taskforce. 120

While neurotechnology can restore and improve brain function, these products may well be expensive and limited only to those who can afford it.<sup>121</sup> This may result in people from lower socioeconomic areas or developing countries being unable to access life changing medical care and enhancements.

As neurotechnology continues to be integrated into society, wage disparity may deepen the equity gaps in society. The exact cost of neurotechnology products is currently hard to ascertain. As an example, it has costed roughly \$40,000 USD for some users to replace an ATI-made neurostimulator implant that was rendered obsolete after an implanting company shut down, and its software was no longer accessible. 122

Inherent bias created by the cost of technology may cause companies to operate under a *social media business model*, that allows free services in exchange for collection and use of data. Neurotechnology companies may advertise discounted products if customers consent for them to use their brain data. This is a dangerous possibility that means already vulnerable communities may be faced with making decisions to effectively compromise their right to privacy in order to access beneficial technology.

If lower socioeconomic groups are priced out of neurotechnological products and services, the data collected and any future changes made based on this data, will be biased. As medical intervention with neurotechnology is very new, it is reasonable to believe that reforms and upgrades will be made to the technology predicated on this biased data – which favours those who can afford the relevant products or services. The inherent problem is that changes will be made to suit the demographic of data that is being collected and will disenfranchise those not yet engaging with neurotechnology. Harvard Researchers have discussed how algorithmic bias will be evident in any form of AI as it impacts medical data. Bias must be acknowledged and mitigated to ensure that it does not 'exclude, oppress or denigrate' vulnerable populations.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 The UK ICO raises the prospect that data will be largely harvested from neurotypical people, leaving neurodivergent customers with potentially biased and ill-equipped products. 124 Discrimination may also take place if devices are not trialled on varied and numerous groups of people. 125 These forms of algorithmic bias, which can effect the use of AI in neurotechnologies, could become embedded in neural devices. This is particularly so where neurotechnologies are used on children, people with neurological disorders or socially marginalised individuals. 126

Regulations should be in place to ensure that researchers and companies are actively working against inputting any bias into future products, services or upgrades. This can be done by ensuring there is regular discussion about possible biases in data collection and that researchers are from diverse backgrounds and are aware of potential data bias.

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# 6 Chapter 4: Future areas of concern

While there are a myriad of human rights challenges associated with neurotechnology, it is important to consider how these issues will arise in different circumstances. The background paper has sought to discuss, at a high-level, just a few of the applications of neurotechnology which may raise complex questions in Australia.

## 6.1 People with disability

It is estimated that approximately 4.4 million Australians have a disability.<sup>127</sup> Substance abuse and neurological disorders account for more than 10% of global disease – with the two most common mental disorders being anxiety and depression.<sup>128</sup> However neurotechnology offers greater possibility to treat and prevent many of these conditions.

## **Benefits**

There are numerous positive examples of neurotechnologies being used to improve the lives of people with disability. For example, neurotechnology has been used to restore the vision of a user who had been completely unable to see for over 16 years, allowing them to discern shapes and letters again. <sup>129</sup> Similarly, cochlear implants have also been used to restore functional hearing to an estimated 1 million people worldwide. <sup>130</sup>

People suffering from paralysis are experiencing quality of life improvements thanks to neurotechnology. The technology has been developed to allow devices to decode speech from brain activity, allowing people to communicate with the external world.<sup>131</sup>

One research participant and recipient of a neurotechnological product, Mr Copeland, highlights the potential of the technology. Mr Copeland was left a paraplegic after a car accident. He has since become the first person to control a robotic arm and recover his sensations of touch though implantation in the cortex of the brain. 132 Mr Copeland described the neuroprosethetic as

very intuitive to control, ... I don't have to strain, it really is just as easy as thinking move and grasp; in that way, it is kind of an extension of myself, but I also see it as a tool that I'm controlling that is separate from myself.<sup>133</sup>

This has allowed Mr Copeland to play video games, fight in a 'lightsabre' duel and even shake hands with former President Barack Obama.<sup>134</sup>

Neurotechnology can also led to greater understanding of how memories are stored. This has led to neurotechnologies capable of improving memory **Protecting Cognition: Background Paper on Neurotechnology and Human Rights,** December 2023 performance by up to 20%. For patients suffering conditions such as Alzheimer's disease, stroke or head injuries, this is a promising treatment.

It is due to these profound capabilities of neurotechnologies that people with disability are most at risk to the harms of the technology. When faced with the opportunity to treat previously untreatable conditions or regain dignity and quality of life it is hard to imagine that few will say 'no'. This inherently creates a power imbalance between people with disability seeking treatment or improvement of life and those that develop, deploy and maintain the products. Such imbalances raise further questions.

## **Negatives**

Despite the potentially positive impacts for people with disability, several pertinent risks arise which must be questioned when engaging with the technology. What processes are in place to ensure that neurotechnology users, who often receive implantable BCIs, are supported for the life of the device? How will updates be transmitted to the implanted BCI? What will happen to BCIs as they become replaced by more advanced BCIs? How can users be protected in the event of a neurotech company's dissolution? Can genuine informed consent be obtained?

The physical health risks of implantable BCIs are well noted and physical harms are already being realised. One example is Second Sight, which provided visually impaired users with a form of artificial vision to help them see again. With over 350 patients globally, this neurotechnology assisted many people. However, in 2019-2020 Second Sight discontinued its product and nearly went insolvent. This resulted in some users literally having their implants 'turned off' as their artificial vision 'went dark'. While some report that the implants still work, at this stage there is little indication that users can have the technology fixed if it malfunctions. 137

Difficulties may also arise when an implantable device is removed. NeuroVista was a company which made a device which signalled to users when an epileptic fit was about to occur, allowing users to take measures to avoid or minimise it. <sup>138</sup> In 2013, NeuroVista ran out of money and began forcibly removing the implantable devices. One user spoke of her sense of deep trauma and grieving after having the device forcibly removed, claiming she would have done anything to keep it – she even attempted to re-mortgage her house to buy the device to evade removal. <sup>139</sup> The device had allowed her to live confidently and happily, but after its removal she stated:

I have never again felt as safe and secure ... nor am I the happy, outgoing, confident woman I was ... I still get emotional thinking and talking about my device ... I'm missing and it's missing.<sup>140</sup>

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 The removal, decommissioning or end of life of an invasive BCI raises issues under article 25 CRPD to the enjoyment of the highest attainable standard of health rights – especially where removal results in disability or physical or mental injury returning or being experienced.

A key difficulty highlighted here is that neurotechnology users require significant and continued support for the life of the device, irrespective of the economic viability of the product itself. This may leave people to fend for themselves if they are left with redundant technology in their heads with little means of seeking remittance or support.

## Informed consent and impaired decision making

Article 12 CRPD recognises that people with disability enjoy legal capacity on an equal basis with others in all aspects of life. Article 12 directs State Parties to ensure that all measures relating to the exercise of decision-making capacity provide for appropriate, effective and necessary safeguards. It is critical that this be applied in the context of neurotechnological treatments.

International treaty bodies and experts, such as Special Rapporteurs, continue to recommend targeted and concrete measures to reduce and eliminate medical coercion and forced psychiatric treatment. It is imperative that the provision of neurotechnological treatments align with human rights obligations.

Generally speaking, inappropriate expectations about a product or device have been identified as a genuine impairment to informed consent.<sup>141</sup> Users of BCIs may also have pre-existing cognitive impairment which can adversely impact their ability to provide initial and continuing informed consent. More concerning is the proposition that, by way of the implantation process, associated cognitive changes may disrupt such informed consent processes.<sup>142</sup> A person should be supported to make informed decisions, consistent with article 12.

In the exercise of informed consent, power asymmetries at play in the context of medical decision-making need to be addressed.<sup>143</sup> Power imbalances undermine users as passive recipients of care instead of active right holders.

Informed consent is especially important as it allows people to choose whether or not to engage with neurotechnology. Any such, consent may be illusory when people with disability must make a choice that is starkly binary: consent to the conditions set or do not receive the technology.

It is also important to note that there will likely be many people who are considered to be 'neurodivergent' who rightly do not consider neurological treatment via BCIs necessary or desirable. It is of the utmost importance that the medical profession respects the needs and desires of all people and do not force neurological devices onto people.

Commented [C5]: OAIC note: We note that the Privacy Act Review proposes to clarify that consent must be voluntary, informed, current, specific and unambiguous, and that the Government has agreed-in-principle with this reform. This may be relevant to consider either in this section or section 7.1/Chapter 5.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 In addition to being provided with the necessary supports in decision-making, any treatment provided to people with disability/mental health disorders should align with a recovery-based model and preferably be provided in a community setting. The Special Rapporteur on Health recommended concerted efforts continue to be exercised globally to shift mental health care away from the predominant medical model.<sup>144</sup>

People with disability must not be assumed to lack decision-making ability on the basis of having a disability. All people should be provided with the appropriate supports to exercise their legal capacity, and a person's decision-making ability must be considered in the context of available supports. In practice, this would mean that a person is considered to have decision-making capacity if they can exercise that capacity with the provision of supports. Supported decision-making is encouraged to support people with disability to make, communicate and participate in decisions that affect their lives.<sup>145</sup>

Given the risks associated with informed and impaired decision-making, stringent risk assessments must be conducted before any implantation. Surgery must not be performed unless an individual is completely and undoubtedly aware of all possible consequences of implantation. Legislation relating to the exercise of decision-making capacity in the context of treatment provision must include the necessary safeguards. Where possible less invasive means of implantation should be utilised, such as endovascular implantation, where the same goals can be achieved.

## 6.2 Children and young people

Young people and children may be especially vulnerable to any side effects of long-term use of neurotechnologies as their minds are still developing. Although such side effects are unknown, if they exist at all, the best interests of children must be central to any use of neurotechnology (in alignment with article 3 of the Convention on the Rights of the Child (CRC)). This is especially urgent as neurotechnologies are already being used by children and young people.

### **Education**

Neurotechnologies may be used in the education sector in the hope that academic performance can be improved.

Primary school children in China were being required to wear non-implantable BCI headsets which record concentration levels during class. The collected brain data was stored on a teacher's computer and later shared with parents without the child's consent.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 The UK ICO notes that there is increasing interest in the use of neurotechnology in the education sector. It further notes the likelihood in the long-term (five to seven years) of the higher education sector using BCIs to monitor student concentration and stress levels and to further improve cognitive processes to boost student performance.  $^{148}$ 

Education is not the only application of neurotechnology for children. Virtual and augmented reality systems can also be supported by brain control for entertainment purposes. 149 With the risk of metaverse and extended reality technologies, it can be expected that the interaction of children with neurotechnologies will only increase.

#### Metaverse

New and emerging technologies (such as the metaverse) provide organisations with increased opportunities to accumulate and utilise the personal information of children – including brain data. The risk of privacy and security invasions for children and young people in the metaverse (inherited from underlying technologies or emerging from the new digital ecology) may be prolific.

In the metaverse, children and young people face a wide range of privacy intrusions and security risks, including:

- The management of massive data streams
- · Pervasive user profiling activities
- · Unfair outcomes of AI algorithms
- Safety of physical infrastructures and human bodies.<sup>152</sup>

The personal data involved in the metaverse will likely be 'more granular and unprecedentedly ubiquitous to build a digital copy of the real world'. This is especially the case as metaverse technologies collect and process data such as brain wave patterns. He

It is likely that there will be an increase in the use of neurotechnology to connect brain waves to gaming and metaverse experiences to allow for immersive experiences for users.<sup>155</sup>

The UK ICO has noted that neurotechnology is being used for games which allow players to operate drones remotely via neurotechnology. <sup>156</sup> It is expected that there will be greater uptake of such technology for gaming in the medium term (four to five years), with more significant uptake in the use of neurotechnology of modulating technologies aimed at gaming. <sup>157</sup>

## The rights of children

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 Online privacy and safety measures in respect of neurotechnology should be developed in accordance with article 3 CRC, which requires that the 'best interests' of the child be a primary consideration in all actions concerning them. This is one of the four guiding principles of the CRC and should be a primary consideration in the digital environment.<sup>158</sup>

When considering the best interests of the child, regard should be had to 'all children's rights, including their right to seek, receive and impart information, to be protected from harm and to have their views given due weight' in addition to ensuring transparency over the criteria applied to determine best interests. Where rights are limited to protect children from online harms, limitations must be lawful, necessary and proportionate. Maximising children's privacy and securing their personal data is itself a 'crucial means of acting in their best interests'. 160

Children's privacy should not be construed narrowly as relating only to data protection measures, and should recognise the importance of children's autonomy and choice over their private lives. A best interests approach may require implementing clear boundaries to prevent practices that both infringe upon children's rights and are contrary to their best interests, including by curtailing routine and indiscriminate digital surveillance measures.<sup>161</sup>

## Neuromarketing and children

The rise of targeted marketing and the negative impacts such advertising can have on children is well reported – such as increasing problems such as obesity, early alcohol consumption or smoking cigarettes or e-cigarettes.<sup>162</sup>

The Special Rapporteur on the right to privacy estimated that:

The online advertising market for children could be worth 1.7 billion by 2021, with more than 72 million pieces of data collected for each child by online advertising companies before the child reaches the age of 13.163

However, the use of neurotechnologies to collect brain data which can be sold and used by companies to advertise to children could allow microtargeted advertising on a scale and impact not yet seen, with serious effects on children and young people as their minds and sense of self develops.

Neuromarketing is a technique which can involve embedding subliminal stimuli with the intention of eliciting a desired response (e.g. someone choosing one product over another) without people consciously registering.<sup>164</sup>

General comment No. 25 (2021) on children's rights in relation to the digital environment states:

Practices that rely on neuromarketing, emotional analytics, immersive advertising and advertising in virtual and augmented reality environments

Commented [eSafety6]: OAIC note: The Privacy Act Review report made a number of recommendations in relation to the privacy rights of children that may be helpful to refer to either here or in section 7.1. This includes:

- Requiring entities to have regard to the best interests of the child as part of considering whether a collection, use or disclosure is fair and reasonable in the circumstances (proposals 16.4 and 12.2), which the Government has agreed to in-principle
- Introducing a Children's Online Privacy Code to, among other things, address how the best interests of the child should be supported in the design of online services (proposal 16.5), which the Government has agreed to.

Commented [NL7]: OAIC note: The Privacy Act Review proposes to prohibit direct marketing and targeting to children unless the direct marketing or targeting is in the child's best interests (proposals 20.5 and 20.6). Government has agreed-in-principle to these proposals. This may be relevant to refer to either in this section or in section 7.1.

**Protecting Cognition: Background Paper on Neurotechnology and Human Rights,** 02 July 2023 to promote products, applications and services should also be prohibited from engagement directly or indirectly with children. 165

# 6.3 Military application

As with many new and emerging technologies, militaries from around the world are beginning to pay close attention to neurotechnologies. Military applications of neurotechnologies can broadly fall into three categories:

- BCIs
- Neurotechnical enhancement
- Neurotechnological systems for deception, detection and interrogation.<sup>166</sup>

The application of this technology could see personnel treated for physical and psychiatric injury as well as to enhance a combatant's effectiveness by improving cognitive and emotional capacities – or even permitting neural remote control of weapons.<sup>167</sup>

The experimental use of such technologies have increased in the past decade, <sup>168</sup> with one notable example being the Defence Advanced Research Projects Agency (DARPA), a research agency of the United States Department of Defence. <sup>169</sup>

The UK Ministry of Defence has even claimed that brain interfaces could allow for the manipulation of the physical world by thoughts alone – such as opening a door handle to an aircraft from anywhere in the world.<sup>170</sup> Lieutenant Colonel of the United States Air Force, Brian Moore has even predicted that BCIs have "... the potential to revolutionise military dominance much the same way nuclear weapons have done".<sup>171</sup>

The application of such technology in warfare is concerning, but so to is its use on military personnel. In military settings, there will be particular concerns surrounding consent and vulnerability in adopting neurotechnologies due to the hierarchical nature of military service. 172

## 6.4 Criminal application

One of the most advanced areas of legal scholarly discourse surrounds neurotechnology and its application in the criminal justice system. Unsurprisingly, neurotechnologies which provide insights into the human mind raise a host of ethical and legal concerns. The application of the technology may range from enhanced interrogation, non-consensual admissions of guilt and new forms of 'lie detection' technologies amongst others.<sup>173</sup> This may result in

**Protecting Cognition: Background Paper on Neurotechnology and Human Rights,** December 2023 adverse human right outcomes for individuals accused of crimes ranging from minor infraction, political dissidence and even murder.<sup>174</sup>

#### Lie Detection

Lie detector mechanisms, specifically polygraph testing, have been in use in the detection of falsehood since the 1940s.<sup>175</sup> Considering recent technological advances, and scepticism towards traditional polygraph tests, there is consideration as to whether the involvement of neurotechnology as a means of lie detection is an effective alternative.

The 'guilty knowledge test' is a technique which relies on the measurement of brain activity to determine if a subject is lying. Also known as 'brain fingerprinting', operators can currently detect the presence of concealed information through the monitoring of brain waves via electroencephalogram (EEG) signals.<sup>176</sup> With the development of neurotechnology, TMS or Transcranial Direct Stimulation (TDS) can cause changes in brain activity, altering a person's physiological responses. Through such stimulation, operators can disrupt two of the four categories of cognitive processes required for deception: information management and risk management.<sup>177</sup> As such, administration of TDS and TMS has demonstrated differences in the subject's ability to detect and protect themselves from making riskier decisions, which in this case would be divulging the truth when they may have a guilty conscience. 178 Another measure to detect falsehood upon stimulation by TDS and TMS was the slowing of reaction time whenever a response was untruthful.<sup>179</sup> As such, informed authorities may be able to detect this delay in response and question the subject further based on the presumption that they are concealing knowledge about the matter.

One of the most pressing issues in using such technology during a criminal investigation is its impact on the privilege to remain silent and not to self-incriminate. This principle does not apply to material that 'exists independently of the will' of the subject including blood samples, fingerprints and documents acquired pursuant to a warrant. However, seeing that neurotechnology has the ability to directly alter the way a witness or suspect provides evidence, which would usually require their cooperation and will to do so, this has serious implications to their right to silence.

## **Memory Recovery**

The retrieval of accurate eyewitness testimonies during criminal justice proceedings is an ongoing matter of concern. Considering the difficulty in obtaining reliable testimony from witnesses who are in acute shock, in addition to the malleability of memories, turning to neurotechnology to enhance memory retrieval may sound appealing.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 Vedder and Laming observe that non-invasive neurotechnology can also have applications in memory recovery where TMS is administered in areas of the brain responsible for memory retrieval such as the temporal lobes and hippocampus. 182 It primarily acts by reducing the occurrence of false memories and conceptual labelling, allowing for a more literal recall of events. 183 The fact that TMS is non-invasive and has relatively short-term effects contributes to the appeal that this may be a promising mechanism to be used in a criminal justice context.

Neurotechnology can also have a role in the retrieval of long-term memories where the event in question occurred decades ago. Current methods of memory retrieval such as cognitive interviews and hypnosis impede upon the accuracy of the information recalled or require a highly trained interviewer to have any useable effect. In Canada, a patient had undergone neurosurgery for the treatment of morbid obesity by suppressing their appetite using DBS electrical impulses.<sup>184</sup> Neurosurgeons discovered that a positive side effect of the surgery was that the patient could recall autobiographic memories of events occurring more than thirty years ago. 185 These memory retrieval effects were said to be persistent as this was an invasive procedure involving an implant. 186 In allowing such neurotechnology to intervene in individual through processes, there is a real risk of breach of the right to mental privacy, and freedom of thought.<sup>187</sup> The concern around this notion is that memories, will be recovered via an intrusion into a person's mental privacy and integrity, when they would otherwise be forgotten.<sup>188</sup> Likewise, considering the malleability of long-term memories, the permissibility of memory recovery technology could open doors to malicious application of this kind of intervention, including memory alteration.

## **Criminal Responsibility**

The inclusion of neurotechnology in the criminal justice system can also have significant implications for the manner in which cases are heard, even altering the tests used in court.

In determining whether a person is criminally responsible for the crime committed, they must have the requisite mental state, or *mens rea*, at the time they committed the crime.<sup>189</sup> The premise behind this principle is that 'it is generally neither fair nor useful to subject people to criminal punishment for unintended actions or unforeseen consequences unless these resulted from an unjustified risk'.<sup>190</sup> Due to direct intervention with the offender's mind, the lines between sole responsibility and 'third party' involvement are blurred when neurotechnology is involved which can have implications as to how the current legal tests apply.

Australian Human Rights Commission Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 For example, when it comes to crimes committed due to an impulse where the offender is not physically able to resist themselves from committing the crime, there may be difficulties in satisfying the mens rea requirements of the said crime. In an age where the use of BCIs are expanding from their conventional application in medicine, BCIs could be installed to alert a person with a severe psychiatric disorder associated with impulsive behaviour of such an impending impulse through detection of neural changes.<sup>191</sup> The thought behind this is that the offender can act to prevent this impulse before its onset. This is also the case where the BCIs themselves provide therapeutic relief with the subject having full autonomy as to when the stimulator is turned on.<sup>192</sup> In this circumstance where the offender is aware that they may commit a crime but actively ignores it, despite the offender not being cognitively aware when the crime is committed, criminal responsibility may be traced back to the moment they ignored the implant's notification or turned off the BCI.193 Similarly, where this BCI malfunctions, the court will have to consider this as an external influential factor either in the analysis of mens rea or as a mitigating factor during sentencing.<sup>194</sup>

## Sentencing

Neurotechnology is also thought to extend to applications after adjudication, as part of the sentencing process or even as an alternative to incarceration. The basis behind this compared to conventional means of sentencing is that there is a greater focus on rehabilitation by reducing the risk of reoffending.<sup>195</sup> It is argued that the preferred forms of rehabilitation such as cognitive behavioural therapy and education programs are favoured over more biological approaches which would include neurotechnology.<sup>196</sup> However, the conventional solutions may fail to consider the 'extensive interplay of the environment and biology and the plasticity of the brain in response to environmental influence' and that more effective forms of rehabilitation ensure public safety.<sup>197</sup>

By reducing tendencies which lead to a pattern of criminal behaviour, these interventions do not act as a 'biological fix'<sup>198</sup>. Examples of such mechanisms include neurotechnology which identifies neural precursors which trigger feelings of aggression and then stimulates the brain to calm the subject down, allowing the subject to make rational decisions after obstructive influences, such as aggression, are no longer present.<sup>199</sup>

In the Netherlands, a judge can impose mandated mental health treatment after incarceration where the period of treatment carries from four years or as long as the judge deems necessary.<sup>200</sup> As such, neurotechnology may be offered as part of such mandated mental health treatment in an effort to aid the process for rehabilitation and eventual reintegration into society.

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023 When offering neurological interventions in place of conventional sentencing or incarceration, it may be questionable whether full and informed consent has been provided. Especially in cases where the consent to use of neurotechnology could be used transactionally for sentence reduction or an earlier parole period, it could be argued that the offender is formally consenting to treatment despite their preference not to – this is known as leveraged consent.<sup>201</sup>

It is crucial that offenders agree to such interventions voluntarily as such treatments involve an invasive biological intervention compared to traditional psychotherapies which are done collaboratively with the patient.<sup>202</sup> That being said, in a study published in 2019 surveying participants convicted of sexual offences, the participants believed that their freedom of choice would not be compromised on account of potential coercion of legally motivated treatment.<sup>203</sup> That being said, participants highlighted there would need to be requirements for "thorough explanation[s] of the purpose, risks and benefits of the treatment options", and "adequate time to process this information" so that they could receive medical advice.<sup>204</sup> As such, the treatment offered should be the least invasive neurointervention, ensuring that the treatment prescribed is not disproportional to the severity of the crime committed.

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# 7 Chapter 5: Legal Concerns

The novel nature of neurotechnologies present a myriad of legal questions which must be considered. The Background Paper seeks to highlight a few pertinent areas where neurotechnology may challenge existing legal frameworks.

## 7.1 Privacy Problems

The *Privacy Act 1988* (Cth) (Privacy Act) is the foundational piece of privacy legislation in Australia. Currently the Privacy Act has no express protection for brain data or mental privacy.

However, the current definition of Personal Information and its subset class of Sensitive Information may include brain data in limited circumstances – primarily related to information about the health of individuals. A number of provisions may operate to limit the circumstances in which Personal Information/Sensitive Information about the health of individuals is covered, for example in respect of certain research activities.<sup>205</sup>

'Personal information' is broadly defined within the Privacy Act as:

information or an opinion about an identified individual, or any individual who is readily identifiable:

- (a) whether the information or opinion is true or not; and
- (b) whether the information or opinion is recorded in a material form or not.<sup>206</sup>

Accordingly, what is considered as personal information will vary on whether the person can be identified or is reasonably identifiable in the circumstances. Common examples of personal information are an individual's name, signature, address, telephone number, date of birth, bank account details, employment details, commentary or opinion about a person and 'sensitive information' – which includes (amongst other things) health or genetic information.<sup>207</sup>

Accordingly, while not expressly referred to, the current definitions of Personal Information and Sensitive Information would appear to cover brain data obtained in a medical context.

## Privacy Act 1988 (Cth) Review Report

The Australian Attorney-General's Department is currently undertaking a <u>review</u> of the <u>Privacy Act</u>, which would see it updated and fit-for-purpose in respect of an increasingly digitised world.

Commented [L8]: OAIC note: We disagree with the statement that the current definition of personal information, and its subset class of sensitive information, only includes brain data in limited circumstances. While information may be sensitive information because it is health information about an individual (as defined in s 6FA of the Privacy Act), a broader range of brain data may also fall within the general definition of 'personal information'. For accuracy, we recommend aligning the commentary in this section more closely with our previous comments in response to your consultation on the United Nation's Human Rights Council Advisory Committee's (UNHRCAC's) study on the impact, opportunities and challenges of neurotechnology (sent by Rebecca Brown on 5 June 2023) which set out further information about both definitions in the context of neurotechnology.

Commented [L9]: OAIC note: The exceptions for research create a separate framework to comply with, are a limited public interest exception and only exempt entities from compliance with certain Australian Privacy Principles (APPs) (for example, it is not an exception to APP 11), but this framing suggests that there is no coverage or that the definition of personal or sensitive information is impacted. We suggest revising the language to provide a more general statement that coverage of the Privacy Act is not absolute, for example: The Privacy Act contains limited public interest exceptions and some exemptions that impact how the Privacy Act applies in certain situations or to certain entities.

In addition, we suggest citing ss 6C, 6D, 7B, 7C, 16A and 16B as examples rather than ss 95A and 95AA.

lt may also be clearer if you include this content after the full discussion about the definition of personal information

Commented [L10]: OAIC note: This sentence suggests the definition of personal information only captures brain data obtained in a medical context, which we do not agree with. For example, where brain data records an individual's attitudes towards different topics and that information is linked to an identified or reasonably identifiable individual that would be personal information. We recommend revising the language for greater accuracy. You may find Rebecca Brown's 5 June email helpful in this regard.

Commented [eSafety11]: OAIC note: We note that the Government released their response to the Department's final report on 28 September so we suggest referring to the Government response here and throughout the section. To assist you we have noted the Government's response to the proposals identified in the section below.

We also note that the uplifts to the Privacy Act will combine to create a strengthened regime overall and so it may be helpful to provide a broad-picture overview of the themes of reform, for example:

The Government has committed to progressing consideration of reforms to Australia's privacy framework under five key areas of focus: bringing the Privacy Act into the digital age, uplifting protections, increasing clarity and simplicity for entities and individuals, improving control and transparency for individuals over their personal information and strengthening enforcement. These reforms will create a

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, 02 July 2023
One aspect of the reforms is amending the definition of personal information, which the Government has agreed to in-principle. This includes changing the word 'about' in the definition of personal information to 'relates to' to clarify that personal information is an expansive concept that includes technical and inferred information. This would be supported by a non-exhaustive list of information that may be personal information (where it also satisfies the definition of personal information) to assist entities to identify the types of information that could fall within the definition. If certain proposals are adopted as part of this review, brain data and mental privacy may receive better protection by way of implication. For example, one possible amendment is to introduce a non-exhaustive, high level, principles-based, technology-neutral list of Personal Information. In particular this non-exhaustive list Relevantly for the purposes of brain data, the Privacy Act Review Final Report states that the list cwould include:

One or more features specific to the physical, physiological, genetic, mental, behavioural, economic, cultural or social identity or characteristics of a person.<sup>209</sup>

These changes may better protect mental privacy because a broader range of brain data would be more clearly captured as personal information, It is possible that physical, physiological, genetic, mental and/or behavioural characteristics of a person may extend to include brain data and protect mental privacy. While the exact language of the final list is not finalised, it is plausible that this list is broad enough to capture brain data and even protect mental privacy reducing uncertainty about when brain data is covered by the Privacy Act.

The Attorney-General's Department review report also recommends the inclusion of a statutory tort for serious invasions of privacy<sup>210</sup> that are intentional or reckless in the Privacy Act.<sup>211</sup> The <u>Commission provided input</u> on this very issue and noted the need for the tort to include negligent acts of privacy invasion, in addition to the need for the tort to be non-restrictive.<sup>212</sup> It is an open question on how such a tort could be used to protect mental privacy and brain data.

The Attorney-General's Department also intends to amend the Privacy Act to require that the collection, use and disclosure of personal information must be fair and reasonable in the circumstances.<sup>213</sup> This would creates a positive obligation that requires entities captured by the Privacy Act to consider the foreseeable risks and impacts to individuals caused by information handling through neurotechnology at the beginning of a project. Accordingly, this may provide a baseline protection of brain data and mental privacy. This test would also require be supported by certain legislated factors, including but not limited to consideration of the kind, sensitivity and amount of personal information

Commented [eSafety12]: OAIC note: Our understanding of this proposal is that the list is a guidance tool rather than a list of information that meets the definition of personal information - it still needs to meet the definition (see pp 28-29 of the Final Report). We have provided some recommended drafting that goes to the point of how the proposals in relation to the definition of personal information could more clearly capture brain data as that seemed to be the ultimate purpose of including this proposal in the background paper.

Commented [C13]: OAIC note: The Government has agreed in principle with this proposal.

Commented [C14]: OAIC note: The Government has agreed in principle with this proposal.

Commented [eSafety15]: OAIC note: It may be helpful to also refer to the proposal to require organisations to conduct a PIA for high privacy risk activities. This proposal supports the fair and reasonable obligation to encourage entities to take a 'privacy-by-design' approach to their personal information handling so that they consider privacy impacts at the outset of their project, rather than respond to them after they have impacted an individual's privacy.

Commented [NL16]: OAIC note: We have made a slight adjustment to highlight how these relate to the test.

**Protecting Cognition: Background Paper on Neurotechnology and Human Rights,** December 2023 being collected, used or disclosed and the risk of unjustified adverse impact of harm, among other considerations.

While the Privacy Act may not expressly protect brain data or mental privacy, it may do so implicitly. It is expected that if proposed reforms to the Privacy Act are adopted, the protection of mental privacy and brain data may also be improved.

## 7.2 Consumer Technology

Some of the biggest risks of neurotechnology will be realised as products are developed and deployed outside of therapeutic and medical fields and provided to consumers more broadly. The medical applications of neurotechnologies are quite stringently regulated in Australia and other countries. However, consumer products operate in an environment largely free of the types of targeted regulation and safeguards that are seen in the therapeutic and medical contexts.

The Commission is concerned by how consumer-oriented BCIs, especially non-implantable BCIs, are not sufficiently regulated. Unlike implantable BCIs or those with medical applications, consumer products operate in an insufficient regulatory environment.<sup>214</sup>

There are already regulations in Australia for the development, testing and use of neurotechnologies in medical applications. Human rights risks are likely to be amplified as neurotechnologies are adapted for broader consumer consumption without the same level of regulation in place.

Neurotechnological intellectual property, which is developed for medical application, can be pivoted and adapted to a consumer market. For example, while some BCIs allow users who are paralysed to operate computers, it isn't difficult to imagine this same technology being sold to gamers for hands-free gaming.

While the risks of products which are purely consumer-oriented are troubling, attention must also be paid to medical products which will be adapted for consumer products. Large-scale neurotechnological products will likely become commonplace in the not-so-distant future. For example, Neuralink just won approval on 26 May 2023 from the US Food and Drugs Administration (FDA) to conduct its first tests on humans.<sup>215</sup> Although Neuralink's products may have aims to assist patients, it is possible this technology may also be pivoted to a consumer market in the future.

Irrespective of how the technology makes its way to consumers, neurotechnologies are becoming increasingly available for direct-to-consumer products for recreational or mental augmentation purposes.<sup>216</sup> Without the

**Protecting Cognition: Background Paper on Neurotechnology and Human Rights,** 02 July 2023 rigorous safeguards in place for medical purposes the effects of these consumer products remain unclear.

For example, non-invasive BCI products are rapidly proliferating outside of a regulated environment. One such example is <u>Apple's recent patent</u> for AirPods capable of monitoring brainwaves. Although non-invasive BCIs will often be used for similar purposes as invasive BCIs, because they do not require medical implantation, they often fall outside of medical regulation in consumer settings.<sup>217</sup> This is especially true for neurostimulation commercial devices using TMS or transcranial direct current stimulation for which the effects are not fully understood – possibly causing adverse consequences for users.<sup>218</sup>

One risk to consumers is where neurological products overpromise on their capability to improve health and wellbeing, which can lead to negative outcomes for consumers, especially where the BCI is implanted. Further, the risks and obstacles of products must not be underestimated, or this too will lead to adverse outcomes.<sup>219</sup>

Equally, brain data collected by consumer products could be monetised and exploited by companies, employers or governments. The combination of brain data and other personal data collected online (from web browsing, smart phones, smart watches etc) might allow certain brain characteristics to be identified – such as attention or vigilance.<sup>220</sup> This may lead to 'neurotype' profiles being created about users to allow for 'neuromarketing' or other exploitative tailored digital targeting.<sup>221</sup> While the use of such information for marketing is problematic, if taken a step further it becomes disturbing. For example, the use of such information may allow political parties to better manipulate voters with highly personalised messaging. Moreover, this data could be used to identify individuals based on certain characteristics, such as the example of sexual orientation outlined above, leading to discrimination by certain state and non-state actors.

Furthermore, the implantation of non-therapeutic invasive neurotechnology involving a medical procedure (e.g. surgery to insert an implant into the brain) will require the surgeon to obtain informed consent regarding the procedure to insert the device, but not the operation and terms and conditions relating to the device once it has been implanted. There are a number of risks that consumers will need to be aware of in deciding to implant a device – including service life, the availability of spare parts, what will happen if the company responsible for the device has been deregistered. Concerns arise that significant decisions such as this ought not be left to boilerplate contracts with fine print terms.

The regulatory gap between medical and consumer neurotechnological products must be addressed. The introduction of consumer protection

Protecting Cognition: Background Paper on Neurotechnology and Human Rights, December 2023 regulations and laws across the globe must be ready for a wave of neurotechnological products in the future.

#### **Australian Consumer Law**

The Australian Consumer Law (ACL) is contained in schedule 2 of the *Competition and Consumer Act 2010* (Cth) and will likely apply to consumer neurotechnologies as the Australian Competition and Consumer Commission (ACCC) and Product Safety Australia regulate the supply of consumer goods.

The ACL applies to corporations and persons carrying on a business within a State or Territory and to 'consumers' as defined by the Act.<sup>222</sup> It is questionable if users paying for neurotechnologies will meet the statutory definition of 'consumer' as this often requires that they are acquiring goods or services, the price of which is less than \$40,000 AUD.<sup>223</sup> However it is possible that neurotechnologies for consumers will naturally aim to reach a price point below \$40,000 to ensure greater take up by consumers.

In particular the ACL provides guarantees regarding the supply of goods in respect of (amongst others) acceptable quality and fitness for purpose which may impact consumer-oriented neurotechnologies.<sup>224</sup>

Acceptable quality means that a product:

- is safe, durable and free from defects
- has an acceptable appearance and finish
- does everything that similar products are commonly used for.<sup>225</sup>

However there are no set rules for deciding whether a product is of acceptable quality, or how long a product should last – which is problematic when considering implantable BCIs which will necessarily require a longer product life.

To determine if a product meets acceptable quality, the following factors need to be considered:

- What kind of product is it, and how does it compare to similar products?
- What is it made of and how was it made, and how does this compare to similar products?
- How much did it cost, and how does it compare to products of a similar price?
- What maintenance may be needed to keep the product operating?
- Did the business or manufacturer make any claims about quality, or how long the product could last for?

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- Did the business warn the consumer about any defects, or warn against the product's use in a certain manner?
- How old is the product, and how long do similar products normally last?
- Was the product sold new or second-hand?
- Has the product been used in a way it wasn't designed for?

It is likely that consumer-oriented neuroethological products would need to answer such questions to ensure they are of acceptable quality for consumers.

The fitness for purpose guarantee will also be important as this guarantee applies when:

- a consumer tells a business they want to use a product for a particular purpose
- the consumer buys the product based on the advice of the business
- the business advertises in any way that the product can be used for a particular purpose.<sup>227</sup>

Where a supplier fails to meet a guarantee, such as acceptable quality or fitness for purpose, the remedy may be repair, replacement or refund and/or compensation for damages and loss.<sup>228</sup> Obviously, replacement parts and expertise need to be available for consumers to avail themselves of repairs. A concern when it comes to neurotechnology is the availability of these remedies if the supplier goes into liquidation (as discussed above in respect of people with disability). A consumer might be left with a degrading piece of technology in their body on which they have come to rely which may not be able to be repaired.

At least in theory, the remedies available under the ACL to protect consumers appear to be adequate to compensate consumers in case of failure (an entitlement to repairs, spare parts, damages and consequential losses).

The ACL also contains a product safety scheme to all consumer goods and product related services supplied in Australia. The ACCC and state and territory consumer protection agencies are responsible for monitoring the market to detect unsafe goods and identify ways to address hazards or encourage safe practices. This can be through consumer awareness campaigns, safety warning notices, product recalls, product bans or mandatory safety standards.

The relevant Commonwealth Minister may also make 'information standards'. Information standards require a person not to supply, offer for supply, or manufacture, possess, or have control of goods or services which do not comply with a relevant information standard.<sup>229</sup> The issuing of a comprehensive information standard for neurotechnology is one way that neurotechnology

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might be regulated to protect consumers utilising non-therapeutic neurotechnology.

# 7.3 Neurotechnology in the Workplace

[**Note:** The Commission is currently seeking legal advice on the application of neurotechnology in the workplace.]

Commented [eSafety17]: OAIC note: To the extent the application of the employee records exemption is discussed we would be interested in seeing this section prior to publication.

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# 8 Chapter 6: The Road Ahead

It is intended that this background paper sparks conversations about the human rights and legal questions raised by neurotechnology. Although it's not a comprehensive survey of all human rights and applications of the technology, this background paper ought to have provided a high-level summary of neurotechnology and associated challenges.

However, if Australia and the international community are to respond to these challenges more must be done. Foremost, it must be decided if new neurorights must be created to protect the human mind – or if we would be better placed to interpret and apply existing rights more broadly to cover the spectrum of challenges associated with neurotechnology. This is a fundamental first step which must be taken to ensure human rights can best safeguard the brain.

Given the numerous applications of neurotechnologies and the breadth of people who will be impacted – Australia must begin conducting a regulatory gaps analysis to determine where legislative shortcomings are identified which may allow for harms to occur. Where such shortcomings are found concrete recommendations must be made and enacted to protect human rights.

Unless these actions are taken, Australia risks falling into the same cycle as numerous countries before it. Waiting too long to address new technologies harms before taking action to mitigate harm. Technology develops at a rapid pace, which government are unlikely to match. Accordingly, solid evidence-based work must be started early and pro-actively.

The Commission considers that neurotechnology will only become increasingly prevalent in our lives over the coming years. The Australian government must act now before it is too late and more people are adversely impacted.

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## 46<sup>th</sup> Closed Session of the Global Privacy Assembly

#### October 2024

Resolution on Neurotechnology, Human Rights, Data Protection and Privacy/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

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## 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 Recommendation, the following definitions are used:

 Neurodata: data relating to the functioning or structure of the human brain of an identified or identifiable individual that includes unique information about their physiology, health, or mental states<sup>1</sup>, that could make them identifiable or identify, including, an entire group of people.

 Neurotechnology: devices and procedures used to access, monitor, investigate, assess, manipulate, and/or emulate the structure and function of the neural systems of natural persons<sup>2</sup>.

TAKING NOTE OF the rapid and significant advances in neurotechnologies, neuroscience and neurodata collection, as well as their 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 possible use of neurotechnologies beyond the medical treatment and scientific research sectors in compliance with applicable sectoral and ethics standards raises crucial concerns from a human rights perspective. These developments promise profound transformations in the way we live, work, and learn, underscoring the need for ethical consideration and careful regulation to ensure they are only used in ways that benefit all of humanity.

**UNDERSTANDING** that the information derived from neuroscience can influence one's perception of oneself and social interactions, resulting in an essential 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 ethical practices that protect people against any form of discrimination or stigmatization 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 that every advancement is considered with an unwavering commitment to law,

<sup>&</sup>lt;sup>1</sup> definition corresponding to 'Personal brain data' in the OECD Recommendation on Responsible Innovation in Neurotechnology

Definition from the OECD Recommendation on Responsible Innovation in Neurotechnology



ethics and justice, ensuring that technology serves human well-being and not 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 neuroscientific data, which has a direct and profound correlation with cognitive and affective states; which acts as an intimate mirror of our most personal experiences and emotions. It should be considered that given the sensitive nature of this data, which reflects the subtleties of the human mind, its processing should be prohibited unless certain conditions are met in line with the applicable legal framework and the data protection safeguards that are in place, and always for the benefit of the data subject.

**EMPHASIZING** that neurotechnologies should never compromise identity, free will, or personality development. Safeguarding individual control over identity is of paramount importance; it is essential that any technological advancement be made with the utmost consideration for personal autonomy and the integrity of the human being.

**EMPHASIZING** the critical importance of protecting personal information, including neurodata, from unauthorized access, use, 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.

**EXPRESSING** deep concerns about the significant risks to all human rights, including privacy and physical and mental integrity, posed by the widespread use of neurotechnologies and the collection 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 artificial intelligence systems processing 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, 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, 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, in order to ensure that the development and application of neurotechnologies is carried out with the greatest integrity and benefit for humanity.

**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, and human rights; the urgency of addressing these global challenges is recognized. The sensitive nature of neurodata, which can reveal intimate aspects of the human psyche, demands meticulous attention and international cooperation to establish standards and practices -including possible bans- that respect the dignity and autonomy of individuals, regardless of borders.

TAKING NOTE OF some fundamental neurorights defined by the Neurorights Foundation, 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, free will, mental privacy, equal access to neurocognition and to protection against bias and discrimination.

**TAKING NOTE OF** some global initiatives towards the regulation on neurotechnologies, that served as reference point for the present Recommendation, such as: The Declaration of the Inter-American Legal Committe on Neuroscience, Neurotechonolgies and Human Rights, August 2021; OEA- Inter American Declaration of Principles Regarding Neuroscience,



Neurothechnologies, and Human Rights, March 2023; OEA- Inter American Declaration of Principles Regarding Neuroscience, Neurothechnologies, and Human Rights, March 2023; Neurodata Statement Iberoamerican Data Protection Network, September 2023;

**TAKING ALSO NOTE** of the Charter of Fundamental Rights of the European Union, the General Data Protection Regulation and the Al Act, which outline certain provisions regarding neurorights and the use of neurodata.

**RECALLING** the last 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 that this Resolution ensure to:

- Scientific advances in neuroscience and neurotechnological applications uphold human rights and dignity while respecting privacy and personal data protection.
- Highlight 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, notwithstanding the foregoing the adoption of new instruments should be promoted to strengthen 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 information in neuroscience and neurotechnology, with the aim of fostering trust, accountability, and respect for privacy in this rapidly evolving field.
- Establish 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 for
  medical treatment and scientific research purposes, adhering to 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 information in neuroscience and neurotechnology, the aforementioned, taking into consideration the documents related specially the High Standards, we can highlight the following provisions:



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

Where the use of neurodata does not breach human dignity, 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.

Also it must be taken into consideration that in certain cases such as children and adolescents, people with disabilities, deprived of their liberty and others with limited decision making capacity, there may not be any form of valid consent, and consequently controllers will need to consider the possibility of relying on any other legal basis.

Consent forms should be presented in plain language, avoiding technical jargon, 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 prioritize privacy and informed consent in personal data processing, ensuring that neurodata is collected only for specified, explicit, and legitimate purposes, and not further processed in a manner incompatible with those purposes.

Promote policies that protect personal data from being used for the discrimination or exclusion of certain persons or populations.

For this reason, as well as to meet the principle of use of neurodata in a way that respects human dignity, neurodata as a rule should only be used for the benefit of the data subject and in compliance with all data protection conditions and safeguards. The use of neurodata for instance for commercial purposes or in the context of legal processes, employment, or insurance should not be allowed.

#### 3. Data minimisation

Only the minimum necessary neurodata should be processed for the intended purpose.

#### 4. Accuracy

Neurotechnology developers and researchers should implement robust validation of the methods used to collect and analyze reliable and reproducible data and adjust measuring



instruments to ensure the accuracy of the data collected from neuroimaging devices, braincomputer interfaces, and other neurosensing tools.

The aforementioned actions can mitigate inaccuracies arising from technical limitations, environmental factors, and individual variability.

## 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, processing, and potential use of personal brain data collected for health purposes.

#### 6. Security

Appropriate protective and defensive security measures should be embraced to combat potential misuse of neurodata.

Governments and relevant scientific bodies should promote industry or research-based best practices 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 information gained through the application of neurotechnology from unauthorised 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 rigorous security standards, as well as risk management.

#### 7. Proactive measures

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

#### 8. Rights of data subjects

Ensure the exercise of data subjects' rights in neurotechnology, 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 in the rapidly evolving field of neurotechnology.

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

## 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 programes, and certifications, among others to ensure responsible and ethical practices throughout the entire lifecycle of neurodata processing, from collection to storage, analysis, and dissemination.

Guarantee 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, special protections should apply to its processing, similar to other special categories of personal data (e.g., health data).

All forms of neurodata constitute highly sensitive personal data in this sense its processing should be prohibited unless certain conditions are met; given that, in a way, neurodata, in almost all cases would constitute by default health data, and when allowing the unique identification of a person would constitute a permanent form of biometric data, they would entail a higher level of sensitivity than other special categories of personal data, thus its processing, when not prohibited, should be subject to reinforced safeguards and controls.

## 11. Ethical Considerations

Emphasizes 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.

This is why, the 46<sup>th</sup> Global Privacy Assembly therefore resolves to:

#### Commitment to Legislation and Privacy:

- Convene to call to legislators and policymakers 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, 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 privacy and autonomy of individuals.
- 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 and potential risks associated with the use of neurotechnologies and the collection of neurodata.
- Encourage interdisciplinary research and collaboration to address the ethical, legal, and social implications of advances in neurotechnologies and neuroscience.

#### 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.
- Include civil society organizations, researchers, scientists, academics, among others, in dialogue and policy development.

## Rights of data subjects and Training of staffData Subjects:

- Urge neurotechnology developers, providers, and deployers to safeguard data protection and privacy recognized as a fundamental human right.
- 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 data is used.

## **International Cooperation and Standards:**

 Promote international cooperation and exchanges of best practices in the regulation and governance of neurotechnologies and neuroscience. To: \$22

Subject: RE: Extract from reg intel report [SEC=OFFICIAL]

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#### Priority – Rebalancing power and information asymmetries

Issue: Potential for excessive collection and retention of personal information, and practices that erode privacy rights in the application of artificial intelligence

#### Privacy implications of Neurotechnology

In October 2025, the Australian Human Rights Commission (AHRC) released the <u>Peace of Mind Report</u> following a 2 year project on neurotechnology and human rights.

The AHRC argues that neurotechnology is a rapidly developing field with huge potential but also presents significant and complex risks to human rights. In relation to privacy risks, the AHRC notes:

- Neurotechnology exacerbates the privacy implications of technology as it challenges previous distinctions between private and public information – internal thoughts were previously impossible to measure, and thus by default private.
- There are limitations to the consent model of privacy which
  places the onus on individuals to be responsible for their data.
  Ensuring informed choice is particularly important if individuals
  are forced to choose between accessing the benefits of a
  technology at the cost of their neural data privacy or not use
  the technology at all.
- There are ambiguities over whether different kinds of neural data are personal or sensitive information under the Privacy Act.

The AHRC recommends urgent reform of Australia's privacy laws to explicitly protect neural data, calls for plain-English privacy policies and meaningful, informed consent for all users and that the Government resource the AHRC and OAIC to produce guidance on the treatment of neural data and neurotechnology under the Privacy Act.

#### Background

The OAIC provided comments on the Draft Report, and Commissioner Kind participated in a panel as a part of the AHRC's Neurotechnology and Human Rights symposium in June 2024.

<u>Human Rights Commission Neurotechnology Paper</u> <u>Summary:</u> D2025/026445

New York Times reports "In 2021, Chile amended its constitution to include explicit protections for "neuro rights"; Spain adopted a nonbinding list of " digital rights " that protects individual identity, freedom and dignity from neurotechnologies. In 2023, European nations signed the Léon Declaration on neurotechnology, which prioritizes a "rights-oriented" approach to the sector. The Legislatures of Mexico, Brazil and Argentina have debated similar measures. California, Colorado, Montana and Connecticut have each passed laws to protect neural data. In the US, in September, three senators introduced the Management of Individuals' Neural Data (MIND) Act, which would direct the Federal Trade Commission to examine how neural data should be defined and protected.

<u>Financial Times</u>: Unesco has developed the first global ethical framework for managing neurotechnology. This month, member states adopted the Recommendation on the Ethics of Neurotechnology. It calls on governments to guarantee the fundamental right to privacy, including mental privacy by strictly governing the sale or sharing of highly sensitive neural and nonneural data which allows others to infer emotions, attention levels and other mental states.

Neurotechnology is a significant emerging technology which could have high impacts on Australians' privacy especially if deployed in workplaces or health settings. For example, use cases for neurotechnology in Australia, featured in the AHRC report, include LifeBand, a fatigue tracking headband which alerts the worker and manager when a worker becomes dangerously drowsy, and early braincomputer interfaces such as Stentrode which allow people with diseases like MND or ALS to use electronic devices.

The AHRC recommendation to develop guidance provides an opportun for Regulatory Board consider the need for guidance or policy we in this area.



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The OAIC acknowledges Traditional Custodians of Country across Australia and their continuing connection to land, waters and communities. We pay our respect to First Nations people, cultures and Elders past and present.

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