

Protecting Cognition: Human Rights and Neurotechnology

Australian Human Rights Commission

Submission to the United Nations' Advisory Committee to the Human Rights Council

02 July 2023

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1 Commission introduction

- The Australian Human Rights Commission (Commission) welcomes the opportunity to make this submission to the United Nations' Advisory Committee to the Human Rights Council in respect of the <u>call for input on</u> <u>neurotechnology and human rights</u> (Call for Input).
- 2. The role of the Commission is to work towards a world in which human rights are respected, protected and promoted. While the Commission has expertise and knowledge in the area of human rights generally, relevant to the Call for Input, it has also developed specific expertise in respect of human rights and technology.
- 3. This can be seen in the Commission's Human Rights and Technology Project, which was a three-year, national investigation that culminated with the release of the <u>Human Rights and Technology Project Final Report in 2021</u> (Final Report).
- 4. More recently the Commission, in partnership with the Actuaries Institute, published guidance on <u>AI and discrimination in insurance pricing and</u> <u>underwriting</u>.
- 5. The Commission has continued its work in 2023 on human rights and technology. This submission is in addition to other 2023 submissions to date, including:
 - <u>Human Rights in the Digital Age:</u> Global Digital Compact submission to the United Nations' Office of the Secretary-General's Envoy on Technology.
 - <u>Tackling Technology-facilitated Slavery:</u> submission to the United Nations' Special Rapporteur on Slavery on contemporary forms of slavery, including its causes and consequences in response to its call for input on the use of technology in facilitating and preventing contemporary forms of slavery.
 - <u>Safeguarding the Right to Privacy</u>: submission to the Attorney-General's Department in response to the Privacy Act Review Report 2022.
 - <u>Foreign Interference through Social Media</u>: submission to the Senate Select Committee on Foreign Interference through Social Media.
 - <u>Privacy Risks in the Metaverse</u>: submission to the Australian Competition and Consumer Commission as part of the Digital Platform Services Inquiry 2020-25.

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- 6. This submission builds upon the previous work of the Commission to advocate for human rights-centred design and deployment of new and emerging technologies.
- 7. In this submission the Commission addresses several questions posed by the Call for Input's questionnaire. The Commission welcomes further opportunities to provide submissions to the Advisory Committee and Human Rights Council in respect of neurotechnology and human rights.

2 Consultations

- 8. The positions presented in this submission are those of the Commission, informed by the views and opinions expressed by participants throughout a consultation process run by the Commission.
- The Commission facilitated two broad consultations with a range of stakeholders and experts from civil society, business, regulators and government in June 2023. Further targeted consultations were also held with certain stakeholders.
- 10. Participants were provided with a Consultation Invitation when they were invited to attend. The Consultation Invitation set out what the Commission requested stakeholders to bear in mind when engaging in the consultations. It emphasised that participants should consider questions four eight raised in the 'Impact, opportunities and challenges' section of the questionnaire. However, it is important to note that this submission also answers questions not raised during consultations.
- 11. The Commission encouraged invitees to provide written input via email where they were unable to attend the online consultations, or if they wished to further expand upon what was discussed.
- 12. Across all consultations, 47 participants engaged in the Commission's consultations. A further 12 stakeholders provided written submissions.

3 Definitions

13. The Call for Input questionnaire specifically defines neurotechnologies as:

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.¹ 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.²

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14. Throughout this submission the Commission has adopted the same definition. However, it is necessary to further understand and define the different forms of neurotechnology which currently exist.

15. 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.³

3.1 Brain-computer interfaces

16. At the core of neurotechnologies are brain-computer interfaces (BCIs).⁴ BCIs are devices which connect an individual's brain to a computer or device (e.g. a smartphone) 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.⁵ This can operate either by implantation inside of a person's skull or via a non-implantable wearable device (similar to a helmet).⁶

3.2 Non-implantable BCIs

- 17. 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 such as helmets, glasses and wristbands. It is these less invasive wearable BCIs which currently dominate the consumer neurotechnology market.⁷
- 18. Such technology may assist people with expressive or communicative disabilities to better communicate by decoding images in a person's mind.⁸ 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.⁹

3.3 Implantable BCIs

- 19.Some BCIs are implanted via surgery inside of a person's skull and placed directly on the brain.¹⁰ These electrodes then send brain data to a computer for analysis and decoding.
- 20.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.¹¹

3.4 Metaverse

21. The Metaverse is not defined in the Call for Input. For the purposes of this submission the Commission draws upon the definition provided by the <u>XR</u> <u>Safety Initiative</u>:

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), neuro-technologies, 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 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.¹²

4 Introduction to neurotechnology and neurorights

22. Broadly speaking neurotechnology is a scientific discipline which consolidates and connects electronic devices with the nervous system.¹³ This is usually done via implantable or non-implantable BCIs.

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- 23. The rapid advancement of neuroscience and 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.¹⁴ 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 again¹⁵ or improving our understanding of how to treat chronic pain.¹⁶
- 24. However, neurotechnologies also raise profound human rights problems which may require the international community to rethink its very approach to modern human rights.
- 25. 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 1997.¹⁷
- 26. However as technologies improve, the potential application of neurotechnologies multiples. This is especially so when BCIs are utilised in conjunction with artificial intelligence (AI), which is still new and largely untested.¹⁸
- 27. For example, a recent experiment has seen the integrated use of neurotechnology and large language model AI to translate brain activity into words.¹⁹ 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.²⁰ Unlike past technologies 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.
- 28. 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.²¹

29. The decoded brain activity produced:

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.²²

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- 30. However, this isn't the only recent example of the capabilities of neurotechnology:
 - There have already been proof-of-concept studies demonstrating brain-to-brain interaction facilitated by neurotechnology.²³
 - 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.²⁴
 - 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.²⁵
 - 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.²⁶
 - 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.²⁷
- 31. These are just a few examples of the increasing sophistication of these technologies and their ability to revolutionise the way humans live and communicate. However, these examples also demonstrate that neurotechnologies are replete with possible human rights violations.²⁸ For example, if mice can be controlled, could the technology be improved to manipulate human thoughts and actions?
- 32. Not only is neurotechnology's capabilities astounding, so is its application. It is likely that neurotechnology will have a role in:
 - Medical treatment of a range of conditions
 - Consumer gaming, education and meditation
 - Socialising
 - Criminal justice as a potential tool for interrogation
 - Military operations to cognitively enhance combatants or to be used for covert brain-to-brain communication.²⁹
- 33. The need to scrutinise the human rights risks of neurotechnology is of unprecedented importance. This is largely due to the technologies capacity to:

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- 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.³⁰
- 34. 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.
- 35. It is likely that neurotechnologies will only become more pervasive and embedded in the everyday lives of individuals over the coming decade.³¹ 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.
- 36. 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

- 37. There are three broad approaches to protecting the human mind from the adverse impacts of neurotechnologies according to the relevant literature.
- 38. 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.³² The proposal of neurorights has generated lively debate as many question their necessity, effectiveness and if it might lead to 'rights inflation'.³³

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- 39. 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 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.³⁴
- 40. However, such an interpretive approach to extend existing rights and freedoms will require a conscious effort by policy makers across jurisdictions and may be slow to advance with the risk of being outpaced by the rate of technological advancement.
- 41. The final group consider that no novel rights or new interpretations are necessary to protect the human mind. This position is largely outdated and rarely raised.³⁵

4.2 Neurorights

- 42. 'Neurorights' is an umbrella term which encompasses novel rights which protect the human mind.³⁶ 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.³⁷
- 43. 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.³⁸
- 44. 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.³⁹
- 45. 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.

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- 46. 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.⁴⁰
- 47. 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.
- 48. Neurotechnology poses an especially novel risk to human rights as it can leap the boundary between the external world and the internal human mind, 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.
- 49. 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.
- 50. 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).⁴¹
- 51. 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.⁴² These projects have been initiated by organisations such as the:
 - United Nations
 - Inter-American Juridical Committee
 - Committee on Bioethics of the Council of Europe

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- United Nations Educational, Scientific and Cultural Organization (UNESCO)
- Organization for Economic Co-operation and Development (OECD).⁴³

52. 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.44
- 53. 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.⁴⁵ Dr 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?⁴⁶

54. 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.⁴⁷

Protecting Cognition: Human Rights and Neurotechnology, 02 July 2023 55. There is increasing discussion globally 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.⁴⁸
- Spain has included neurodata specific sections in its Digital Rights Charter.⁴⁹
- The United Nations, InterAmerican Juridical Committee and the Council of Europe are all exploring whether existing human rights and freedoms provide sufficient legal protection from neurotechnologies.⁵⁰
- UNESCO has recently made its <u>report</u> on the risks and challenges of neurotechnologies for human rights.⁵¹
- The United Kingdom's Information Commissioner's Office (UK ICO) recently published a <u>paper</u> on neurotechnology.
- 56. Although there are some divergences, neurorights often settle around the discussion of the right to mental privacy, mental integrity and cognitive liberty.

4.3 What is mental privacy?

- 57. Mental privacy simply refers to the right to private thoughts, feelings, memories, emotions and brain data.
- 58. Vint Cerf, Vice President and Chief Internet Evangelist at Google, once stated that 'privacy may actually be an anomaly'.⁵² 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.
- 59. There is already significant commentary and calls for legislative reform about how to protect personal information online.⁵³ It seems a natural progression for those discourses to extend now to the protection of brain data.
- 60. Availability of 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.⁵⁴ Such insights put those with access to the brain data in a powerful position to manipulate people either through direct intervention

Protecting Cognition: Human Rights and Neurotechnology, 02 July 2023 through neurotechnologies or by utilising the brain data to subversively push people towards certain decisions.

- 61.We already know that algorithms are able to 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.⁵⁵
- 62. 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
 - freedom of thought
 - freedom of expression.

4.4 What is mental integrity?

- 63. 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.⁵⁶ 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.⁵⁷
- 64. 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.⁵⁸
- 65. 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.
- 66. Unlike the right to mental privacy, the right to mental integrity has been recognised by various human rights instruments.
- 67. 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.

Protecting Cognition: Human Rights and Neurotechnology, 02 July 2023 68. Further, article 5(1) of the ACHR states:

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

69. 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.

- 70. 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 ECHR.⁵⁹
- 71. 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.⁶⁰

72. 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.⁶¹

4.5 What is cognitive liberty?

- 73. 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.⁶²
- 74. 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.⁶³
- 75. Effectively the right to cognitive liberty contains both positive and negative freedoms. It contains a negative right to be free from external coercive

Protecting Cognition: Human Rights and Neurotechnology, 02 July 2023 control or interference – while also including a positive right to freely control one's own brain.⁶⁴

- 76. 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.

5 Australia's response to neurotechnology

Has your country taken any policy action or initiative in relation to neurotechnology and human rights at the national level?

- 77. The Australian government has taken limited policy action or initiative directly associated with the regulation of neurotechnology as an emerging technology.
- 78. There are also no Australian institutional responses to the human rights implications of neurotechnologies.⁶⁵ This has led to criticism of Australia's responses to human rights and neurotechnology as being under-theorised and lacking a response form regulatory or human rights institutions.⁶⁶
- 79. The Commission's Human Rights and Scrutiny Team is considering a project which seeks to address neurotechnology and human rights. This project would actively consult with relevant stakeholders, as recommended by UNESCO and scholars.⁶⁷
- 80. Broadly speaking the outcome of such a project will be to produce a final report on human rights and neurotechnology including recommendations to best protect human rights in the neurotechnology field.

6 Australia's neurotechnology market

Is there any actor in the public or private sector developing this kind of technology in your country?

81. With one in eight people living with a neurological disorder,⁶⁸ it is unsurprising that from 2014 to 2021 there has been a 700% increase in neurotechnology investment globally.⁶⁹ The broad range of potential applications of neurotechnology increases its viability as an investment option. Protecting Cognition: Human Rights and Neurotechnology, 02 July 2023

82. The UK ICO cites the Regulatory Horizons Council's prediction that the neurotechnology market as a whole could be valued at \$17.1 billion USD by 2026, with the largest segments being neuromodulation, neuroprosthesis and neurosensing.⁷⁰

6.1 Public sector neurotechnology organisations

- 83. Many governments are 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 US government's BRAIN Initiative and the Human Brain Project by the EU, which will contribute \$6.6 billion USD and €1.19 billion respectively.⁷¹ Further:
 - China will invest \$1 billion USD until 2030 in the China Brain Project⁷²
 - Japan will invest 40 billion JPY in its Brain Initiative⁷³
 - Canada invested 267 million CAD in the Canada Brain Research Fund in 2021⁷⁴
 - the UK invested 98 million EUROS between 2011 and 2020.75
- 84. According to Grand View Research, the global market size of BCIs (excluding BRAIN Initiatives) was valued at \$1.52 billion USD in 2021, and expected to grow at a compound annual growth rate of 17.16%.⁷⁶ Based on this data, the NeuroRights Foundation has estimated an expected market value of \$3.93 billion by 2027.⁷⁷
- 85. The Australian federal government recently announced its first <u>National</u> <u>Quantum Strategy</u>, which will see investment of \$101 million AUD in the responsible development of Australia's quantum and artificial intelligence industries.⁷⁸ This will work in tandem with the federal government's \$15 billion AUD <u>National Reconstruction Fund</u> which aims to finance projects which will transform Australia's industry and economy.⁷⁹ One of the priority funding areas is noted as being medical science, however it should be noted that there is no identifiable tied funding for neurotechnology government initiatives.
- 86. From 2016 to 2020, Australia's public investment in neurotechnology totalled \$350 million USD.⁸⁰

6.2 Private sector neurotechnology organisations

87. There has also been significant investment and market value in private companies. According to NeuroTech Analytics' recent report, investment in neurotechnology companies has increased from \$331 million USD to \$7.3

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billion USD over just 10 years.⁸¹ The current overall investment in neurotechnology companies now sits at \$33.2 billion USD, indicating its meteoric expansion and ease in attracting significant capital.⁸² Of 1,400 existing neurotechnology companies, most of them are located in the US (50%) and Europe and the UK (35%).⁸³

- 88. The top five BCI companies by total investments as of 2021, according to NeuroTech Analytics are:
 - Neuralink \$363 million USD
 - Synchron \$130 million USD
 - Kernel \$107 million USD
 - Paradromics \$58.3 million USD
 - Blackrock Neurotech \$10 million USD.⁸⁴

89. Four of the above five companies are based in the US.

6.3 Synchron

- 90. Synchron is an Australian company. It works on implantable BCI devices and is an endovascular BCI leader.⁸⁵ 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.⁸⁶
- 91. In July 2022 Synchron was the first to utilise an endovascular BCI approach in the U.S. after successful implantation. This will have significant implications for the scalability of BCIs as this approach does not require open-brain surgery.⁸⁷
- 92. The technology's assessments measures the impact of tasks such as:
 - texting
 - emailing
 - online shopping
 - accessing telehealth services
 - ability to live independently.⁸⁸
- 93. There are 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.⁸⁹ One other example is Omniscient Neurotechnology which is currently working on personalised brain maps to better understand neurological disease, mental health and brain potential.⁹⁰

7 Awareness of Neurotechnology

Indicate your level of awareness (high/medium/low) in relation to the state of development of neurotechnologies and preparedness to tackle the challenges posed by the early commercialization of these technologies.

- 94. The Commission's level of awareness of neurotechnological development is high – as is its preparedness to engage with the human rights challenges of the technology itself.
- 95. Australian Human Rights Commission President, Emeritus Professor Rosalind Croucher AM, spoke at 'Neurotechnology and the Law Forum' on 01 December 2022 and again at 'Buzzwords: Neurotechnology' on 29 March 2023 about the human rights implications of neurotechnology.
- 96. Australian Human Rights Commissioner, Lorraine Finlay, spoke at 'HELP (Human Rights, Ethics, Law and Policy)' on 17 May 2023 on human rights law and neurotechnology. Commissioner Finlay was also quoted in a recent article noting the profoundly positive impacts of neurotechnology, and calling for caution given the potential human rights risks.⁹¹
- 97. The Commission also ran consultations with key stakeholders (as discussed above at [2]) to inform its position for this submission.
- 98. The Human Rights and Scrutiny Team within the Commission is seeking to develop a key project on human rights and neurotechnology in the coming years. This project is still in the development phase and subject to funding.
- 99. The Commission has expertise in assessing and mitigating the human rights risks of new and emerging technologies as part of its <u>Technology and Human</u> <u>Rights</u> portfolio.

8 Human rights impacted by neurotechnology

What human rights will be mostly impacted by the development and use of neurotechnologies? Identify the three rights most impacted and briefly explain why.

100. 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.⁹² For the purpose of answering this question, the focus has been in respect of existing rights. However there must be more considered engagement on the question of whether to introduce novel neurorights. This is especially Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology**, 02 July 2023 important as it is still unclear on how exactly the technology could undermine human rights.⁹³

101. Although there is a diversity of rights which will be impacted, for the purposes of answering the questionnaire we have limited our discussion to just three existing human rights – noting that neurorights are not currently human rights enshrined in international instruments.

8.1 Right to privacy

- 102. 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. Unchallengeable statements about internal thoughts and feelings such as 'that's how I feel' can now be analysed, examined and tested.⁹⁴
- 103. 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.⁹⁵
- 104. 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.
- 105. 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.
- 106. 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.⁹⁶ The collection of brain data will make it possible to track, analyse and predict the actions and attitudes of individuals about anything from political leaning, sexual orientation or health status.⁹⁷ The risk to privacy is of the utmost concern in respect of brain data due to its implied use.
- 107. Neurotechnology products will record vast quantities and varieties of mental data which may be accessed without genuine consent.⁹⁸ There are already issues about individuals 'giving away' their online personal data to third parties through collection notices.

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- 108. The usage of such neurodata 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.
- 109. 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.⁹⁹ There has already been research claiming that computer-vision algorithms could predict sexuality from a single image of a person's face.¹⁰⁰ 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.
- 110. 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.¹⁰¹ 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.
- 111. 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.
- 112. 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.
- 113. 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 history, biometric information etc) can, accumulatively, provide a detailed profile of an individual dubbed the 'mosaic effect'.¹⁰²
- 114. 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

Protecting Cognition: Human Rights and Neurotechnology, 02 July 2023 the inclusion of brain data, this will allow sensitive personal information to be extracted or inferred about a person on an unprecedented scale.¹⁰³

115. 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.

116. 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.

- 117. Despite the importance of private brain data in making us who we are, article 17 is silent on mental privacy.
- 118. The right to privacy is also protected in many other international instruments.¹⁰⁴ 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.¹⁰⁵

- 119. 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.
- 120. 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.
- 121. 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.
- 122. 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.¹⁰⁶ Namely, individuals will still engage with privacy-adverse products and services even where they are

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highly aware of the risks. This does not mean that individuals do not care about their privacy. For example, 74% of individuals have safety concerns in relation to being targeted by products or services.¹⁰⁷ A further 76% consider it is unfair when personal information is used to make predictions about them, while a further 85% consider it is unfair or very unfair for their personal information to be shared with other companies.¹⁰⁸ It is possible that with the usage of neurotechnology these rates of concern would only increase.

- 123. 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
 - their perception of how it is being used.¹⁰⁹
- 124. This is particularly the case where the difference becomes explicit and too contrasting.¹¹⁰ 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.¹¹¹
- 125. 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.¹¹² This is especially so in respect of implantable BCIs which are invasive and difficult to remove often requiring medical intervention, such as brain surgery.
- 126. 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.¹¹³ 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.¹¹⁴
- 127. 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.

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- 128. The traditional model of privacy regulation places great emphasis on informed 'choice' as an effective safeguard for data and privacy.¹¹⁵ However, the privacy paradox and numerous behavioural studies demonstrate that placing the onus on individuals to protect their own data is insufficient.¹¹⁶
- 129. 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'.¹¹⁷
- 130. The privacy paradox, illusion of choice and power imbalances may all contribute to individuals being unable to utilise neurotechnology without relinquishing their privacy.
- 131. The Consumer Policy Research Centre in its <u>In whose interest? Why</u> <u>businesses need to keep consumers safe and treat their data with care</u> (Working Paper) put forward two alternative approaches to protecting data in Australia – which may have global application.
- 132. 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.¹¹⁸
- 133. 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.¹¹⁹

134. While the Working Paper is specific to Australia and does not discuss neurotechnology, the Commission would call upon the Human Rights Council to consider how similar models may be applicable, or could be adapted, to inform the better protection of brain data globally.

8.2 Freedom of thought, conscience and religion or belief

135. Neurotechnology will potentially challenge what it means to have freedom of thought and agency over our own lives. As discussed above at [30] BCIs can be used to override the thoughts and actions of laboratory mice. The application of neurotechnologies goes further and has the potential to Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology**, 02 July 2023 decipher and alter perceptions, behaviours, emotions, cognition and memory – all fundamental aspects of what makes us who we are.¹²⁰

136. This will allow the technology to one day manipulate people's beliefs, motivations and desires.¹²¹ 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:

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*).¹²²

- 137. 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.¹²³
- 138. 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.¹²⁴
- 139. 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.

- 140. 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.¹²⁵
- 141. 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

Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology,** 02 July 2023 concerning that, despite the protection in Article 18, this could lead to persecution based on a person's belief.

8.3 Right to equality and non-discrimination

- 142. 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.
- 143. Particularly, article 25 UDHR stipulates:

everyone has the right to a standard of living adequate for the health and well-being of himself and of his family

144. 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.

- 145. To prevent deepening inequality, the right to equal access to mental augmentation has been proposed by NeuroRights Foundation and the Neurotechnology Ethics taskforce.¹²⁶
- 146. While neurotechnology can restore and improve brain function, these products may well be expensive and limited only to those who can afford it.¹²⁷ This may result in people from lower socioeconomic areas or developing countries being unable to access life changing medical care and enhancements.
- 147. 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.¹²⁸
- 148. 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.
- 149. If lower socioeconomic groups are priced out of neurotechnological products and services, the data collected and any future changes made

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based on this data, will be biased. Because 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.¹²⁹ Bias must be acknowledged and mitigated to ensure that it does not 'exclude, oppress or denigrate' vulnerable populations.

- 150. 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.¹³⁰ Discrimination may also take place if devices are not trialled on varied and numerous groups of people.¹³¹
- 151. 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 background and are aware of potential data bias.

9 Greater regulation for consumer markets

What are the biggest challenges and risks that the development, test and use of neurotechnologies pose to human rights? Will such risks be amplified by the development of consumer-oriented neurotechnologies?

- 152. 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 or guardrails that are seen in the therapeutic and medical contexts.
- 153. 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.¹³²
- 154. There are already regulations in Australia for development, testing and use of neurotechnologies in medical applications (see [13.1]). Human rights risks

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are likely to be amplified as neurotechnologies are adapted for broader consumer consumption without the same level of regulation in place.

- 155. 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.
- 156. 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.¹³³ 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.
- 157. Irrespective of how the technology makes its way to consumers, neurotechnologies are becoming increasingly available for direct-toconsumer products for recreational or mental augmentation purposes.¹³⁴ Without the rigorous safeguards in place for medical purposes the effects of these consumer products remain unclear.
- 158. For example, non-invasive BCI products are rapidly proliferating outside of a regulated environment. 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.¹³⁵ 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.¹³⁶
- 159. 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.¹³⁷
- 160. 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 watched etc) might allow certain brain characteristics to be identified such as attention or vigilance.¹³⁸ This may lead to 'neurotype' profiles being created about users to allow for 'neuromarketing' or other exploitative tailored digital targeting.¹³⁹ While the use of such information for

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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.

- 161. 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.
- 162. The regulatory gap between medical and consumer neurotechnological products must be addressed. The introduction of consumer protection regulations and laws across the globe must be ready for a wave of neurotechnological products in the future.
- 163. Consideration should be given to the creation of, or improved resourcing of, a Therapeutic Goods Administration (as discussed below at [13.1]) style government body to:
 - assess and ensure the safety of non-therapeutic neurotechnology
 - ensure that entities selling neurotechnology are appropriately insured and/or have the financial means to compensate consumers
 - oversee a government 'safety net' fund to assist and protect consumers when the companies responsible for legacy technology are no longer around to remove legacy technology or replace parts
 - implement information standards relating to neurotechnology (potentially adopting an informed consent model for the level of information and warnings consumers can expect when purchasing neurotechnology for non-therapeutic uses).
- 164. Without sufficient regulations in place, it is likely that countries will fall into the same cycle of failing to regulate proactively and then have to play catchup as people experience harm.

10 Vulnerable groups

What groups are more vulnerable or at risk? Please, identify three and explain why.

165. Given the complex and interdisciplinary application of neurotechnology, it is both difficult and problematic to identify just three groups that are more vulnerable to risk. However, given the structure of the questionnaire we have limited our response to our areas of expertise and which reflect matters discussed during consultation.

10.1 People with disability

166. It is estimated that approximately 4.4 million Australians have a disability.¹⁴⁰ Substance abuse and neurological disorders account for more than 10% of the global disease burden – with the two most common mental disorders being anxiety and depression.¹⁴¹ However neurotechnology offers greater possibility to treat and prevent many of these conditions.

10.1.1 Benefits

- 167. There are numerous positive examples of neurotechnologies being used to improve the lives of people with disability. This submission will briefly summarise just some examples to highlight how impactful the technology can be.
- 168. In one instance, 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.¹⁴² Similarly, cochlear implants have also been used to restore functional hearing to an estimated 1 million people worldwide.¹⁴³
- 169. 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 again.¹⁴⁴
- 170. One research participant and recipient of a neurotechnological product, Mr Copeland, demonstrates 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 brain implantation in the cortex of the brain.¹⁴⁵ Mr Copeland described the neuroprosethetic as

Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology**, 02 July 2023 very intuitive to control, ... I don't have to strain, it really is just as easy as thinking move and grasp; so 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.¹⁴⁶

- 171. This has allowed Mr Copeland to play video games, fight in a 'lightsabre' duel and even shake hands with former President Barack Obama.¹⁴⁷
- 172. Neurotechnology can also led to greater understanding of how memories are stored. This has led to neurotechnologies capable of improving memory performance by up to 20%.¹⁴⁸ For patients suffering conditions such as Alzheimer's disease, stroke or head injuries, this is a promising treatment.
- 173. 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.

10.1.2 Risks

- 174. 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?
- 175. 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.¹⁴⁹ With over 350 patients globally, this neurotechnology profoundly 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.¹⁵⁰
- 176. 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.¹⁵¹ In 2013, NeuroVista ran out of money and began

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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 remortgage her house to buy the device to evade removal.¹⁵² 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.¹⁵³

- 177. 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.
- 178. 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.
- 179. One option may be to create an independent body, entirely funded by neurotechnology companies. This body could continue to provide support for users for the life of a product so that users are not left behind when a particular product is no longer profitable. Another option may be to ensure interoperability of neurotechnologies to allow for continued maintenance and support across organisations.
- 180. It should also be noted that given the impact neurotechnologies will have on people with disability, they should be actively involved in the design and deployment of the technology alongside continuing governance processes.

10.1.3 Informed consent and impaired decision making

- 181. 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 decisionmaking capacity provide for appropriate, effective and necessary safeguards. It is critical that this be applied in the context of neurotechnological treatments.
- 182. 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.

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- 183. Generally speaking, inappropriate expectations about a product or device have been identified as a genuine impairment to informed consent.¹⁵⁴ 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.¹⁵⁵ A person should be supported to make informed decisions, consistent with article 12.
- 184. In the exercise of informed consent, power asymmetries at play in the context of medical decision-making need to be addressed.¹⁵⁶ Power imbalances undermine users as passive recipients of care instead of active right holders.
- 185. 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. 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.
- 186. In addition to being provided with the necessary supports in decisionmaking, 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.¹⁵⁷
- 187. 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 decisionmaking ability must be considered in the context of available supports. In practice, this would mean that a person is considered to have decisionmaking 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.¹⁵⁸
- 188. 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

Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology**, 02 July 2023 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.

10.2 Young people and children

189. 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.

10.2.1 Education

- 190. Neurotechnologies may be used in the education sector in the hope that academic performance can be improved.
- 191. Primary school children in China were being required to wear nonimplantable BCI headsets which record concentration levels during class.¹⁵⁹ The collected brain data was stored on a teacher's computer and was later shared with parents without the child's consent.¹⁶⁰
- 192. 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.¹⁶¹
- 193. 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.¹⁶² With the risk of metaverse and extended reality technologies, it can be expected that the interaction of children with neurotechnologies will only increase.

10.2.2 Metaverse

194. 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.¹⁶³ 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.¹⁶⁴

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195. 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.¹⁶⁵
- 196. The personal data involved in the metaverse will likely be 'more granular and unprecedentedly ubiquitous to build a digital copy of the real world'.¹⁶⁶ This especially the case as metaverse technologies collect and process data such as brain wave patterns.¹⁶⁷
- 197. 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.¹⁶⁸
- 198. The UK ICO has noted that neurotechnology is being used for games which allow players to operate drones remotely via neurotechnology.¹⁶⁹ 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.¹⁷⁰

10.2.3 The rights of children

- 199. 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.¹⁷¹
- 200. 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.¹⁷² 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'.¹⁷³
- 201. 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,

Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology**, 02 July 2023 including by curtailing routine and indiscriminate digital surveillance measures.¹⁷⁴

10.2.4 Neuromarketing and children

- 202. 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.¹⁷⁵
- 203. 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 13.¹⁷⁶

- 204. 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.
- 205. 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 to promote products, applications and services should also be prohibited from engagement directly or indirectly with children.¹⁷⁷

10.3 Socioeconomic disadvantaged and marginalised groups

- 206. Socioeconomically disadvantaged and marginalised communities may be disproportionately affected by neurotechnology policies due to the anticipated high price of products and services. Such expense may force those wishing to enjoy the benefits of neurotechnology to waive their rights to privacy in exchange for discounted or free products. Such a business model has operated in social media where the product/service/platform is free to join and use but organisations monetise user data for profit.
- 207. Brain data is an especially sensitive form of personal data. While the risks of waiving one's right to privacy online is problematic, to do so in respect of brain data may have serious and unintended consequences. The Commission is deeply concerned by any neurotechnology service or product whose business model is built on the monetisation of brain data. Such a business

Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology,** 02 July 2023 model will only perpetuate existing social inequalities and may even create entirely new problems not yet considered.

11 Risk assessments

What methods can be used to identify and assess the potential risks and impact of these technologies on human rights, in particular the human rights of persons with disabilities and other groups in vulnerable situations? Will such risks be amplified by the development of consumer-oriented neurotechnologies?

208. One of the most integral ways to best identify, assess and mitigate the adverse impacts of neurotechnologies is to implement a robust regulatory regime which covers the technology in medical, consumer and industrial settings. Any such regulation should also consider the profoundly positive impact this technology can have on people, especially those living with disability. Such regulation does not necessarily have to be a barrier to innovation and can also be a key enabler.¹⁷⁸

11.1 Human rights impact assessments

- 209. A key strategy of protecting human rights in the context of neurotechnologies is the effective use of human rights impact assessments (HRIAs).¹⁷⁹ A HRIA tool assesses how a new product, service, law or policy will engage human rights. They also provide a framework for ensuring adequate rights protections.¹⁸⁰
- 210. HRIAs are increasingly being used by government, the private sector and civil society organisations to measure the risk to human rights posed by their activities, ensure that measures are put in place to address human rights risks, and support the availability of remedies for any human rights infringements.¹⁸¹
- 211. The Commission's previous work has found strong support from the public and private sectors, for the development of HRIA tools and associated guidance.¹⁸² HRIA tools will help to identify and address human rights issues at the earliest stage of the design, development and deployment of new and emerging technologies – such as neurotechnology.
- 212. There has already been support for the use of HRIAs in privacy settings and in respect of facial recognition technology (FRT). In the Commission's recent <u>submission</u> to the Attorney-General's Department on proposed reform to the *Privacy Act 1988* (Cth), the Commission provided in-principle support for the Human Technology Institute's <u>Model Law</u> on facial recognition technology. In

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particular, the Model Law requires organisations to conduct a Facial Recognition Impact Assessment (FRIA) of the potential harms, including the potential human rights risks. This FRIA would be registered, publicly available and could be challenged by the regulator or interested parties.

- 213. As the name would indicate, the FRIA is a more streamlined version of an HRIA specific to FRT technologies. Privacy Impact Assessments are also becoming increasingly commonplace to ensure the safety of user personal information and data.
- 214. The Commission considers HRIA tools to be fundamental for protecting human rights in a more holistic way. Specifically, HRIA tools could address risks to people with disability and other groups in vulnerable situations.
- 215. It is also of note that such due diligence processes are in line with the recently updated <u>OECD Guidelines for Multinational Enterprises on</u> <u>Responsible Business Conduct</u> in respect of actual and potential adverse impacts related to science, technology and innovation.¹⁸³

11.2 Communication

- 216. In addition to regulation and the use of HRIAs, strong communications measures must be in place to communicate human rights and other risks to potential users. UNESCO notes that the following proactive communication measures should be followed by meeting the following steps:
 - Introduce a fair communication/information process which outlines the risks and benefits of a neurotechnology product through institutional channels where experts are directly available.
 - Make available to people competent medical supervision in case of side effects.
 - Provide honest and transparent information regarding the commercial interests of large-scale diffusion of direct-to-consumer products.
 - Provide a clear explanation of the current state of scientific progress in bio-enhancing techniques to mitigate misunderstandings or manipulation of lay people.
 - Neurotechnologies accessing brain data should be ethically designed by default.¹⁸⁴

12 Reaping the benefits, while minimising the harms

From a human rights perspective, what opportunities could the use of neurotechnologies bring? Can these opportunities be balanced against the identified risks and impact?

- 217. Neurotechnology has the potential to vastly improve our understanding of the human mind. This technology has already led to scientists to actively developing treatments for conditions such as:
 - Alzheimer's disease
 - schizophrenia
 - stroke
 - post-traumatic stress disorder
 - depression
 - addiction.185
- 218. If these treatments are effective, there are a myriad of ways in which human rights could be amplified, let alone the positive impact it would have in improving the quality of life for people experiencing mental illness or neurological disorders.
- 219. Research teams are also developing BCIs to allow people with paralysis to spell words on computers and regain the control of limbs be they organic or artificial.¹⁸⁶ Equally neurotechnology which is able to 'read' the mind and transcribe thought into language will be life-changing for those who have lost their capacity to communicate or move.
- 220. Neurotechnologies will help to return capacity to many people, especially those with disability, enabling them to improve and enforce their human rights. Such technologies will undoubtedly improve human rights for many. However, there are also serious human rights risks if guardrails are not put in place.
- 221. To effectively 'balance' risks against positive outcomes it is necessary that:
 - human rights be interpreted to apply to neurotechnologies
 - consideration be given to the creation of a set of neurorights
 - HRIAs be adopted by those developing and deploying neurotechnology
 - regulation be introduced for the medical, consumer and industrial applications of neurotechnology.

13 Is the Australian national framework adequate?

Is the national legal framework adequate to face the challenges that the development, test and use of neurotechnologies pose to human rights? Please explain briefly and indicate the relevant pieces of legislation and whether there are plans to develop any (or further) legislation.

- 222. Generally speaking the brain can be protected via:
 - international human rights law
 - domestic constitutions
 - ordinary domestic law
 - a combination of the above option.¹⁸⁷
- 223. When considering Australia's ordinary domestic laws, the Commission considers that the existing national framework is insufficient to address the human rights challenges posed by neurotechnologies.

13.1 Therapeutic Goods Act 1989 (Cth)

- 224. The *Therapeutic Goods Act 1989* (Cth) is federal legislation that governs products defined as therapeutic goods, which can include medicines, medical devices and biologicals in Australia.
- 225. The *Therapeutic Goods Regulations 2002* (Cth) do not appear to have any express human rights considerations and instead intend to regulate the medical device from the perspective of the physical safety of the user.
- 226. The <u>Therapeutic Goods Administration</u> (TGA) is the authority responsible for evaluating, assessing and monitoring products that are defined as therapeutic goods. The TGA regulate medicines, medical devices and biologicals to help Australians stay healthy and safe.¹⁸⁸ However, there are non-therapeutic uses of neurotechnology which will not be governed by the *Therapeutic Goods Act 1989* (Cth).
- 227. Neither the legislation nor regulation provide adequate human rights protections in respect of neurotechnology beyond medical safety standards mechanisms and obligations.

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13.2 Proposed human rights act

- 228. The Commission has launched its <u>Position Paper: A Human Rights Act for</u> <u>Australia</u> (Position Paper) on 9 March, including a model for a federal Human Rights Act for Australia.
- 229. The proposed Human Rights Act model forms part of a review by the is to be reviewed by the Parliamentary Joint Committee on Human Rights (PJCHR), which accepted <u>submissions until 01 July 2023</u>. It is possible that an outcome of this review will relate to the human rights risks of neurotechnology. The impact of the proposed Human Rights Act is discussed in greater detail from [254].

13.3 Australian Consumer Law

- 230. 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 and the Australian Competition and Consumer Commission (ACCC) and Product Safety Australia regulate the supply of consumer goods.
- 231. The ACL applies to corporations and persons carrying on a business within a State or Territory and to 'consumers' as defined by the Act.¹⁸⁹ 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.¹⁹⁰ 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.
- 232. 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.¹⁹¹
- 233. 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.¹⁹²
- 234. 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.

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- 235. 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?
 - 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?¹⁹³
- 236. It is likely that consumer-oriented neuroethological products would need to answer such questions to ensure they are of acceptable quality for consumers.
- 237. 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.¹⁹⁴
- 238. 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.¹⁹⁵ Obviously, replacement parts and expertise need to be available for consumers to avail themselves of repairs. Of 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.

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- 239. 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).
- 240. However, given the stakes when neurotechnologies are implanted into the brain, additional protections are appropriate (such as a government entity to ensure safety of products and that an entity has appropriate insurance and/or capacity to pay damages into the millions) in addition to TGA-style assessment of the efficacy of the technology ought to be undertaken before a consumer product may go to market.
- 241. 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.
- 242. 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.¹⁹⁶ The issuing of a comprehensive information standard for neurotechnology is one way that neurotechnology might be regulated to protect consumers utilising non-therapeutic neurotechnology.

14 Mental privacy and personal brain data

Does national legislation on privacy and data protection cover mental privacy and/or personal brain data? Please explain.

- 243. The *Privacy Act 1988* (Cth) is the foundational piece of privacy legislation in Australia. Currently the Privacy Act has no express protection for brain data or mental privacy.
- 244. 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.¹⁹⁷
- 245. 'Personal information' is broadly defined within the Privacy Act as:

Protecting Cognition: Human Rights and Neurotechnology, 02 July 2023 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.¹⁹⁸
- 246. 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.¹⁹⁹
- 247. 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.

14.1 Privacy Act 1988 (Cth) Review Report

- 248. The Australian Attorney-General's Department is currently undertaking a <u>review of the Privacy Act</u>, which would see it updated and fit-for-purpose in respect of an increasingly digitised world.
- 249. 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.²⁰⁰ In particular this non-exhaustive list would include:

One or more features specific to the physical, physiological, genetic, mental, behavioural, economic, cultural or social identity or characteristics of a person.²⁰¹

- 250. 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.
- 251. The Attorney-General's Department review report also recommends the inclusion of a statutory tort for serious invasions of privacy²⁰² that are intentional or reckless in the Privacy Act.²⁰³ The <u>Commission provided input</u> on this very issue and noted the need for the tort to include negligent acts of

Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology**, 02 July 2023 privacy invasion, in addition to the need for the tort to be non-restrictive.²⁰⁴ It is an open question on how such a tort could be used to protect mental privacy and brain data.

- 252. 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.²⁰⁵ This would require entities captured by the Privacy Act to consider the foreseeable risks to individuals caused by information handling through neurotechnology. Accordingly, this may provide a baseline protection of brain data and mental privacy. This test would also require consideration of the kind, sensitivity and amount of personal information being collected, used or disclosed and the risk of unjustified adverse impact of harm, among other considerations.
- 253. 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.

15 National Human Rights Act

Is your national institutional framework for human rights well-equipped to address the new challenges posed by neurotechnologies?

- 254. Australia does not currently have a cohesive federal human rights framework.
- 255. However the Commission launched its <u>Position Paper: A Human Rights Act</u> <u>for Australia</u> (Position Paper) on 9 March, proposing a model for a federal Human Rights Act for Australia.
- 256. The Commission's model includes a legislative obligation for public authorities to act compatibly with the human rights expressed in the Human Rights Act (such as the right to 'privacy and reputation' and the 'freedom of thought, conscience, religion and belief') and consider human rights when making decisions.²⁰⁶ This is known as a 'positive duty' and compliance with it would be judicially reviewable.
- 257. The positive duty builds upon the understanding of human rights over more than 10 years of engagement in the parliamentary scrutiny process involving statements of compatibility and review by the Parliamentary Joint Committee on Human Rights (PJCHR).
- 258. The requirement to give 'proper consideration' to human rights applies to making decisions and implementing legislation and policy it is a procedural obligation. The requirement to 'act compatibly' with human rights is a

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substantive obligation on public authorities. Under the proposed Human Rights Act, public authorities would also be required to engage in participation processes where the proposed 'participation duty' is relevant, as part of the 'proper consideration' limb. Compliance with the positive duty would be reviewable by courts (and possibly by tribunals). The positive duty would require decision makers to consider human rights at an early stage, helping to prevent breaches from occurring.²⁰⁷ Further details can be found in the <u>Commission's Position Paper</u>.

259. The Position Paper proposes the inclusion of an interpretive clause in the Human Rights Act stating that courts are to prefer an interpretation that is compatible with human rights, provided that this is consistent with the intention of Parliament, as expressed through the statute under analysis.²⁰⁸ This approach is consistent with, and builds on, the 'principle of legality', a common law principle of statutory interpretation that presumes Parliament 'does not intend to interfere with common law rights and freedoms except by clear and unequivocal language'.²⁰⁹

15.1 Right to privacy

260. The proposed right to privacy and reputation outlined in the Human Rights Act states:

A person has the right—

(a) not to have the person's privacy, family, home or correspondence unlawfully or arbitrarily interfered with; and

(b) not to have the person's reputation unlawfully attacked.

Note: The right to privacy applies to the collection, processing or retention of personal data through all forms of technology, and includes state surveillance measures.²¹⁰

- 261. This proposed right to privacy and reputation implements article 17 of the ICCPR (to which Australia has signed and ratified). The proposed right draws on the wording used in s 13 *Victorian Charter of Human Rights and Responsibilities Act 2006* (Vic), s 25 *Human Rights Act 2019* (Qld) and s 12 *Human Rights Act 2004* (ACT).²¹¹
- 262. The 'note' in the proposed right to privacy and reputation clarifies that privacy rights extend to technological surveillance measures, noting the increased capacity of the state collect personal data and make decisions based on that data through AI.²¹²

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- 263. It does not include express mention of neurotechnologies nor refer to the right to mental privacy. 'Personal data' is not specifically defined in the proposed Human Rights Act, but it could be interpreted to include brain data which is collected and utilised by neurotechnology.
- 264. The inclusion of a right to privacy in the proposed Human Rights Act is especially relevant given previous PJCHR findings in relation to the Committee's review of proposed legislation for compatibility with human rights. The PJCHR's annual report sets out the most commonly listed rights engaged by the legislation which the PJCHR examined and substantively commented on during the year. The 2020 annual report, for example, evidenced the right to privacy as the most commonly engaged with right at 28%.²¹³ This was also true in 2021.²¹⁴ However, as far back as 2016 the right to privacy has been one of the most commonly engaged rights each year.²¹⁵
- 265. Accordingly, the proposed Human Rights Act is capable of protecting brain data, but given the rapid pace with which neurotechnologies are developing, the consideration of any future draft legislation could include whether more express references to the right to mental privacy and neurotechnology are needed.

15.2 Freedom of thought, conscience, religion and belief

266. The proposed right to privacy and reputation outlined in the model Human Rights Act states:

Every person has the right to freedom of thought, conscience, religion and belief. This right includes—

- (a) the freedom to have or to adopt a religion or belief of their choice; and
- (b) the freedom to manifest their religion or belief in worship, observance, practice and teaching, either individually or as part of a community and whether in public or private.

No-one may be coerced in a way that would impair their freedom to have or adopt a religion or belief in worship, observance, practice or teaching.²¹⁶

267. This proposed right implements article 18 of the ICCPR (to which Australia has signed and ratified). The proposed right draws on the wording used in s 14 *Victorian Charter of Human Rights and Responsibilities Act 2006* (Vic), s 20 *Human Rights Act 2019* (Qld) and s 14 *Human Rights Act 2004* (ACT).²¹⁷

268. Freedom of thought, conscience, religion and belief could possibly be interpreted as protecting against mental manipulation via neurotechnology. However, this is unlikely to be the case given the complexities of protecting mental integrity and freedom of thought (as discussed at [4.4] and [8.2] respectively).

16 International regulatory framework

What are the main international regulatory and governance gaps that you have identified as regards neurotechnology and human rights?

- 269. The NeuroRights Foundation published the report, <u>Public Gap Analysis of</u> <u>Existing Human Rights and Neurotechnology</u>, on 6 May 2022.
- 270. This extensive report expressly considers the international regulatory and governance gaps in respect of neurotechnology and human rights. It methodically analyses the:
 - ICCPR
 - Convention against Torture and other Cruel, Inhumane or Degrading Treatment or Punishment
 - ICESCR
 - CRPD
 - International Convention on the Elimination of all Forms of Racial Discrimination
 - Convention on the Elimination of All Forms of Discrimination against Women
 - CRC.

17 International cooperation

What actions would you advocate for to address these gaps and potential human rights impact at the international level? Please elaborate on specific normative or institutional measures you would propose and assess the feasibility of their implementation.

- 271. The OECD published its <u>Recommendation on Responsible Innovation in</u> <u>Neurotechnology</u> in 2019. It is the first international standard for government and industry, which places emphasis on:
 - safeguarding brain data

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- safety assessments
- inclusivity
- scientific collaboration
- stewardship and trust across the public and private sector
- anticipating and monitoring unintended use and/or misuse.²¹⁸
- 272. The Recommendation on Responsible Innovation in Neurotechnology embodies nine principles which focus on:
 - promoting responsible innovation
 - prioritizing safety assessment
 - promoting inclusivity
 - fostering scientific collaboration
 - enabling societal deliberation
 - enabling the capacity of oversight and advisory bodies
 - safeguarding personal brain data and other information
 - promoting cultures of stewardship and trust across the public and private sector
 - anticipating and monitoring potential unintended use and/or misuse.²¹⁹
- 273. These principles provide the foundation of how to maximise benefits, while minimising the harms of neurotechnology.²²⁰

17.1 Defining 'neurorights'

- 274. As noted above, there is divergence on whether it is best to interpret existing rights to apply to neurotechnologies, create new neurorights or some combination of the two approaches.
- 275. Regardless of which approach is taken, greater consideration of the scope of rights aimed at protecting the mind is needed to protect the brain from current and future risks.
- 276. Specifically, if neurorights are introduced into human rights instruments, they must be flexibly defined both in scope and application to ensure such rights have broad application as neurotechnologies develop.
- 277. National human rights institutes and international human rights organisations have an important role to play in bringing together relevant stakeholders in a consultative way to define neurorights and the best way to

Australian Human Rights Commission **Protecting Cognition: Human Rights and Neurotechnology**, 02 July 2023 protect them. The Commission expects that its future work on neurotechnology will assist in this regard and contribute to helping further this conversation.

- 278. Individual countries have already provided some definitions. Chile has a proposed law and constitutional amendment mandating neuroprotection, while the Spanish Digital Rights Charter will also incorporate neurorights (as noted above at [55]).²²¹
- 279. The key is to ensure that our understanding of neurorights, or how existing rights might be defined under existing instruments, is given urgent attention.

17.2 United Nations

- 280. The United Nations should give a specific focus to addressing human rights and neurotechnology, such as action to expand the understanding of traditional human rights to apply to neurotechnology, or the creation of specific neurorights.
- 281. The Office of the Secretary-General's Envoy on Technology should dedicate resources and expertise towards advancing the protection and promotion of neurorights and/or expressly developing an interpretation of existing rights which protect the human mind. In addition to designating funding to do so, the Envoy should deliver a comprehensive framework on human rights and neurotechnology.
- 282. The United Nations should also consider appointing a Special Rapporteur on Neurotechnology and Human Rights. The Special Rapporteur could travel to countries to monitor neurotechnological progress and human rights violations – with an aim to publish reports and ensure that there is public awareness and scrutiny of such developments.
- 283. Existing treaty bodies, such as the United Nations Committee Against Torture, should be encouraged to adopt General Comments on neurotechnology and its interactions with their relevant treaty instruments. This may assist interpretation of existing treaties to apply to neurotechnology.
- 284. A collaborative and international approach is necessary to avoid gaps in human rights regulations being exploited by individuals or organisations. Such gaps may result in questionable neurotechnology products or services being offered in some jurisdictions and not in others. This could have the unintended effect of creating a 'black market' or see individuals and organisations engage in compliance-regime shopping to avoid human rights frameworks or regulation.

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Endnotes

- ¹ Organisation for Economic Co-operation and Development (OECD), '*Recommendation Responsible Innovation in Neurotechnology*' (OECD Legal Instrument, 2019); OECD, '*Neurotechnology and Society: Strengthening Responsible Innovation in Brain Science*' (policy papers, November 2017) 49.
- ² United Nations Educational, Scientific and Cultural Organization (UNESCO), 'Report of the International Bioethics Committee of UNESCO (IBC) on the Ethical Issues of Neurotechnology' (Report, 2021) 5.
- ³ Sjors Ligthart et al., 'Minding Rights: Mapping Ethical and Legal Foundations of Neurorights' (2023) *Cambridge Quarterly of Healthcare Ethics* 1, 3.
- ⁴ The Neurorights Foundation, '*Market Analysis Neurotechnology*' (Report, March 2023) 3.
- ⁵ The Neurorights Foundation, '*Market Analysis Neurotechnology*' (Report, March 2023) 3.
- ⁶ Allan McCay, 'Neurotechnology, Law and the Legal Profession' (Horizon Report for The Law Society, August 2022) *The Law Society of England and Wales* 4; The Neurorights Foundation, '*Market Analysis Neurotechnology*' (Report, March 2023) 3.
- ⁷ The Neurorights Foundation, '*Market Analysis Neurotechnology*' (Report, March 2023) 5.
- ⁸ The Neurorights Foundation, '*Market Analysis Neurotechnology*' (Report, March 2023) 5.
- ⁹ The Neurorights Foundation, '*Market Analysis Neurotechnology*' (Report, March 2023) 5.
- ¹⁰ The Neurorights Foundation, 'Market Analysis Neurotechnology' (Report, March 2023) 14.
- ¹¹ The Neurorights Foundation, '*Market Analysis Neurotechnology*' (Report, March 2023) 14.
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