

Neural Rights: Landmark Ruling

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Imagine a future where consumers could have their minds read, to tell the tale of how and why they buy goods and services, or even how they think about political decisions. The enormously popular book, Homo Deus, by Yuval Noah Harari, the sequel to his blockbuster, Sapiens, explores the dystopian future that awaits from the amplification of Homo Sapiens through technology, and its potential for abuse. This may be a dystopia, depending your point of view, but it is no longer the future. And the law already has something to say about it.

On August 9, 2023, the Chilean Supreme court issued a ruling against a mind-reading device that will have significant repercussions in regulating such devices and protecting “neural rights.”

Privacy rights – to control access to and use of data coming from inside our heads – have been the subject of intense focus by Dr. Rafael Yuste. He is a Professor of Biological Sciences and Neuroscience, and CoDirector of the Kavli Institute of Brain Science and Director of the NeuroTechnology Center (NTC) at Columbia University. Dr Yuste has worked in Chile with the politician and doctor, Guido Girardi, who has served as both senator and president of the Chilean Senate. Girardi has advocated for a number progressive social issues. Of particular importance, he led the introduction of a 2021 constitutional revision in Chile guaranteeing mental privacy, and a law that seeks to define and protect the physical and psychological integrity of individuals.

Girardi purchased the "Insight" device, manufactured and sold by the US based company, Emotiv, Inc. The Insight is described in marketing material as an "EEG headset" for use in connection with "Neuromarketing." Emotiv touts the device's ability to avoid biases inherent in self-reporting in qualitative research techniques, claiming that "consumers make most of their decisions, unconsciously, and can't always express why they prefer a particular design or product, or why it makes them feel a certain way." These EEG headsets "measure brain waves with millisecond accuracy – providing real insights into how someone feels about your products or media. Our EEG headsets are simple to use, and can be used anywhere – allowing research opportunities that were once impossible. By combining neuroscience and qualitative research, you can truly measure consumers preferences."

Touted, as a "quest to democratize brain research," Emotiv says that Insight devices "lower the barrier to entry for researchers in terms of cost and location. Research can now happen anywhere in the world at any time with accurate results." The company says it has been referenced over "19,000 times on Google scholar." A disclaimer on the company's website states "Emotiv products are intended to be used for research applications and personal use only. Our products are not sold as medical devices as defined in EU directive 93/42/EEC. Our products are not designed or intended to be used for diagnosis or treatment of disease." The Chilean Supreme Court does not agree.

When Girardi purchased the device online, he accepted the terms and conditions. When he installed its software on his computer, he opened an account, and again accepted the terms and conditions. Because he was using the free license, he was unable to export or import any copy of the cerebral data the device obtained. He decided not to pay the license and begin the recording of his cerebral information, understanding that it was all recorded and stored in the cloud of the company's servers.

Girardi sued Emotiv. He alleged that he was exposed to the following risks as a result of Emotiv recording and storing his cerebral data: that he could be identified through his stored personal data; the cerebral data could be pirated or hacked; the data could be reused without authorization; the data could be sold or commercialized; he could be subject to digital surveillance; and his data could be used for unauthorized purposes. He alleged Emotiv violated his rights under of articles 11 and 13 of Law No. 19.628 regarding the due diligence and care of personal data.

Emotiv argued that it did not violate Law No. 19.628 because they receive data privacy protection, satisfied even higher standards than the European GDPR, requiring among other things, the pseudonym musician of data that prevents them from being a tribute to any particular person, and that identity is separated from data, and the company, or you did it didn't violate article 13 of the same law, which requires data to be stored only during the use of the account by the user absent legal justifications, because the user was entitled to revoke their consent to its use, which, in this case they claimed Jordi did not do. The company insisted that for scientific investigation the data was completely anonymized, encrypted, and preserved in such a form securely and separated from personal data of the user. Thus, under law, 19.628, the data become "statistical data," meaning data, which, in its origin, or as a consequence of its treatment, cannot be associated to an identified or identifiable individual.

The Intermediate Court of Appeals of Santiago required the Institute of Public Health to respond to Girardi's allegations. The Institute stated that according to Article III of the Sanitary Code and Article 22 of DS No. 895/98 of the Ministry of Health which approved the regulation for the control of products and elements for medical use, the apparatus did not require authorization to be used commercially, and was not required to be placed on the Sanitary Register. The Customs Service likewise was required to report, and informed the courts that the device required a certificate of customs destination unless it was otherwise registered. Because it was not registered, the Insight device did not have a Customs certificate.

The Supreme Court thoroughly reviewed the Chilean Constitutional and national laws, as well as various international agreements on human rights, and ordered the Chilean Institute of Public Health and Customs Service to ensure that the Insight device and the use of data obtained from it comply strictly with applicable law. The Supreme Court also ordered Emotiv to delete all of Girardi's personal data that it recorded and saved

The Chilean Constitution is unique in the world to have an express provision protecting privacy rights concerning "brain activity and information derived from it." On 14 October 2021, the Chilean Congress adopted Law Number 21.383 amending Article 19 of the Chilean Constitution, which provides for the right to life and physical and psychic health. The new provision states that "scientific and technological development must be at the service of people and conducted with respect to life and physical and psychic health." It also states that "the law shall regulate the requirements, conditions and restrictions for its use on people and must especially protect, especially cerebral activity as well as the information derived from it."

In addition the constitutional mandate for protection, the Supreme Court relied on international human rights treaties and declarations that recognize the connection between science and human rights. The International Covenant on Economic, Social and Cultural Rights, adopted by the UN General Assembly in 1966 and came into force in 1976, provides in Article 15 for the right of every person to enjoy the benefits of scientific progress in its applications. The UNESCO Declaration on Science and the Use of Scientific Knowledge and Agenda for the Use of Science, published in 2000, provides that "scientific investigation and research, and the use of scientific knowledge, must respect human rights and the dignity of all human beings, consistent with Universal Declaration of Human Rights, and in light of the Universal Declaration on the Human Genome and Human Rights." The Declaration recognized, the Supreme Court noted, "a special responsibility to avoid applications of science that are ethically wrong or have negative consequences." Finally, the Supreme Court cited the Universal Declaration on Bioethics and Human Rights, also promulgated by UNESCO, published in 2003, which establishes general principles concerning the vulnerability of human health, together with the principle of privacy and confidentiality of interested parties and information that concerns them.

The court also cited Chilean Law No. 20.120, Article 11, which prohibits human cloning and provides that "all scientific investigation on a human being, requires their prior express, free and informed consent." Under this law, there is informed consent when the person who must provide it knows the essential aspects of the research, including its purpose, benefits, risks, and alternative procedures or treatments." Such consent must be provided in a signed writing, and must be obtained each time the terms and conditions are modified.

Thus, the court rejected Emotiv's argument that the data became "statistical" because it was anonymized, because of the requirement of obtaining prior express consent for the use of such information for scientific research, separate from statistical recording, which is expressly regulated in Chile. Information that is obtained for various purposes "cannot be used finally for any purpose, unless the owner knew of and approved of it."

Thanks to the work of Dr. Yuste and Senator Girardi, the Chilean Congress and Supreme Court have taken a firm stand. Scientific methods that read our minds were only science fiction until the last few years, and this requires the government health regulators to pay special attention and review such technologies to prevent or anticipate misuse and to protect human health and dignity.

If device manufacturers and scientific researchers want to learn what tale our thoughts would tell, there must be clear, prior, and express consent for the exact use of those thoughts.

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