

Comité
d'éthique
de l'Inserm



**Converging on the person
Emerging technologies for the common good
XXVIII General Assembly Pontificia Academia Pro Vita
Augustinianum Conference center
February 20-22 2023**

The Cognitive Sciences and Neurotechnology perspective

Hervé Chneiweiss

Declaration of links of interest

Neuroscientist Head Neuroscience Paris Seine (CNRS - INSERM - Sorbonne University)

Neurologist at La Salpêtrière Paris (Neurooncology)

Chairperson INSERM Ethic Committee

Former chairperson UNESCO International Bioethics Committee

Member OECD/BNCT Neurotechnologies Network

Co-Rapporteur Council of Europe and OECD round table "Neurotechnologies and Human Rights: Do we need new rights?" 2022

Member of the scientific council of the Brocher Fondation

Member EBRAINS Science and Society Committee

Member International Brain Initiative Ethics Committee

I declare that I have no conflict of interest concerning the data contained in this presentation

Ethical issues of access to our brain activity

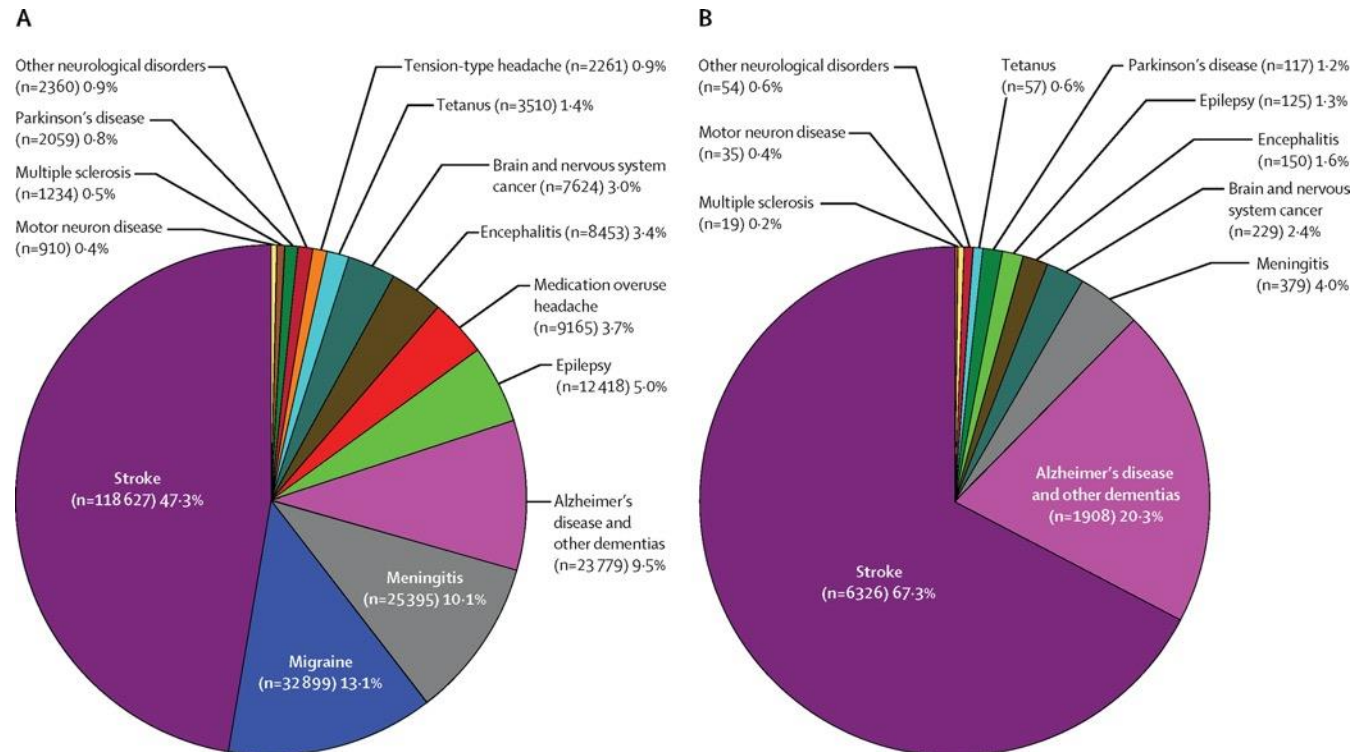
- Brain activity provides information inherent to all human beings regardless of gender, nationality, language, or religion.
- The centrality of the brain to notions of human identity, freedom of thought, autonomy, privacy, and human flourishing makes of paramount importance ethical, legal, and societal impact of recording (“reading”) and/or modulating (“writing”) brain activity through various devices and procedures collectively named neurotechnology.
- Neurotechnology: devices and procedures used to access, monitor, study, evaluate, manipulate, and/or mimic the structure and function of the neural systems of individuals (OECD, 2019)



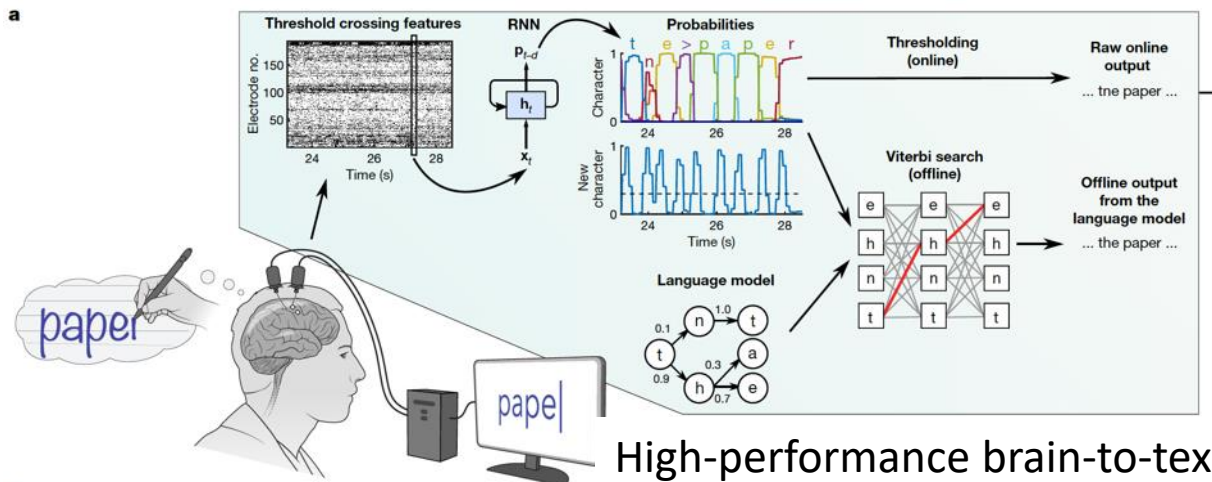
2019 OECD Recommendation on Responsible Innovation in Neurotechnology.
2021 UNESCO IBC report on ethical issues of neurotechnologies
2022 Council of Europe and OECD round table "Neurotechnologies and Human Rights: Do we need new rights? "

Tremendous health issues

Brain diseases, neurological or mental diseases, represent a third of health expenditure, i.e. around 1500 billion dollars each year in the USA and 1000 billion euros in Europe. Hundreds of millions of humans are affected by autism, nervous breakdown, schizophrenia, multiple sclerosis, Alzheimer's disease, stroke or migraine.



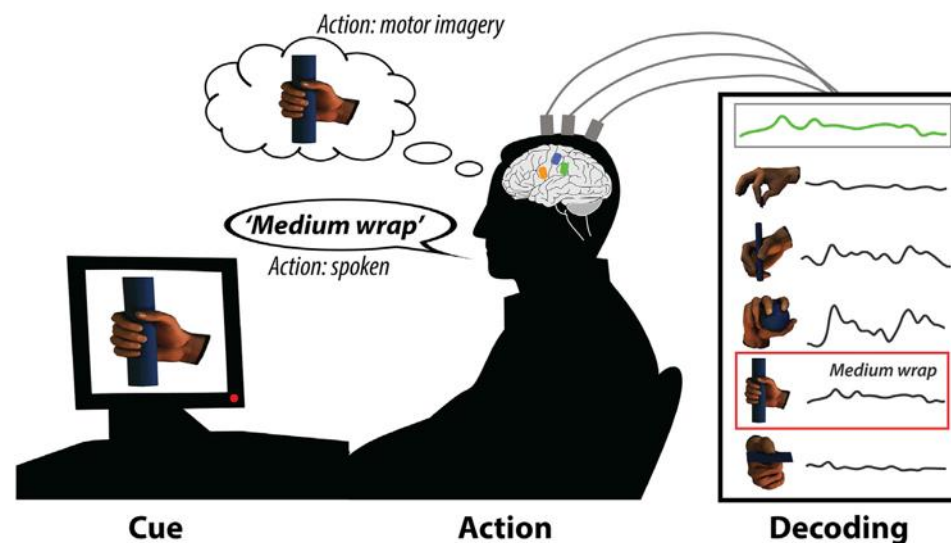
a



Fast Progress in the last 30-y
Cochlear Implants
Deep Brain Stimulation
Brain Machine Interface...

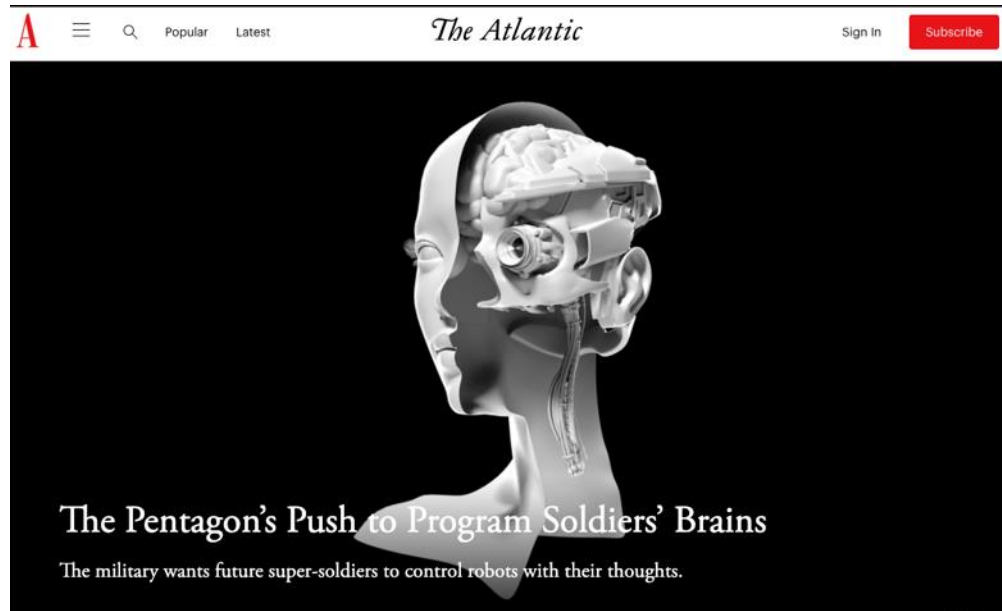
High-performance brain-to-text communication via handwriting
 Nature 2021 doi.org/10.1038/s41586-021-03506-2

Decoding grasp and speech signals from the cortical grasp
 circuit in a tetraplegic human. Neuron. 2022 doi:
 10.1016/j.neuron.2022.03.009.



More and more extra-medical uses Military, Computing, Education, Well-being, Marketing

In 2017, Darpa launched the Neural Engineering System Design project, aimed to achieve a “wireless human brain device that can monitor brain activity using 1 million electrodes simultaneously and selectively stimulate up to 100,000 neurons”



nature biotechnology

[Explore our content](#) [Journal information](#)

[nature](#) > [nature biotechnology](#) > [news feature](#) > [article](#)

News Feature | [Published: 12 August 2019](#)

The business of brain–computer interfaces

[Eric Smalley](#)

[Nature Biotechnology](#) **37**, 978–982(2019) | [Cite this article](#)

2288 Accesses | **2** Citations | **27** Altmetric | [Metrics](#)



The potential to change an individual's behavior

Benefit for the autonomy of the person by restoring, for example, the movement and cognitive capacities of a person with Parkinson's disease

Risk of modification of the capacity for emotional and behavioral control

Risk of taking control of emotional and behavioral capacities

The potential for cognitive enhancement

Neurotechnologies could be used to improve the cognitive, sensory and motor abilities of some patients with neurological or mental disorders

this paves the way for similar technologies to be used by healthy people for enhancement.

To be ethical and responsible, an enhancement technology should not only improve an individual's well-being and quality of life, but also have positive effects on their community and society..

Impact on developing brains

Particular attention will be paid to the impact of neurotechnologies on the brain and behavior of children and adolescents.

The brain of children and adolescents is not a small adult brain, but a brain under construction, in evolution, in dynamics



What is a Normal Brain?

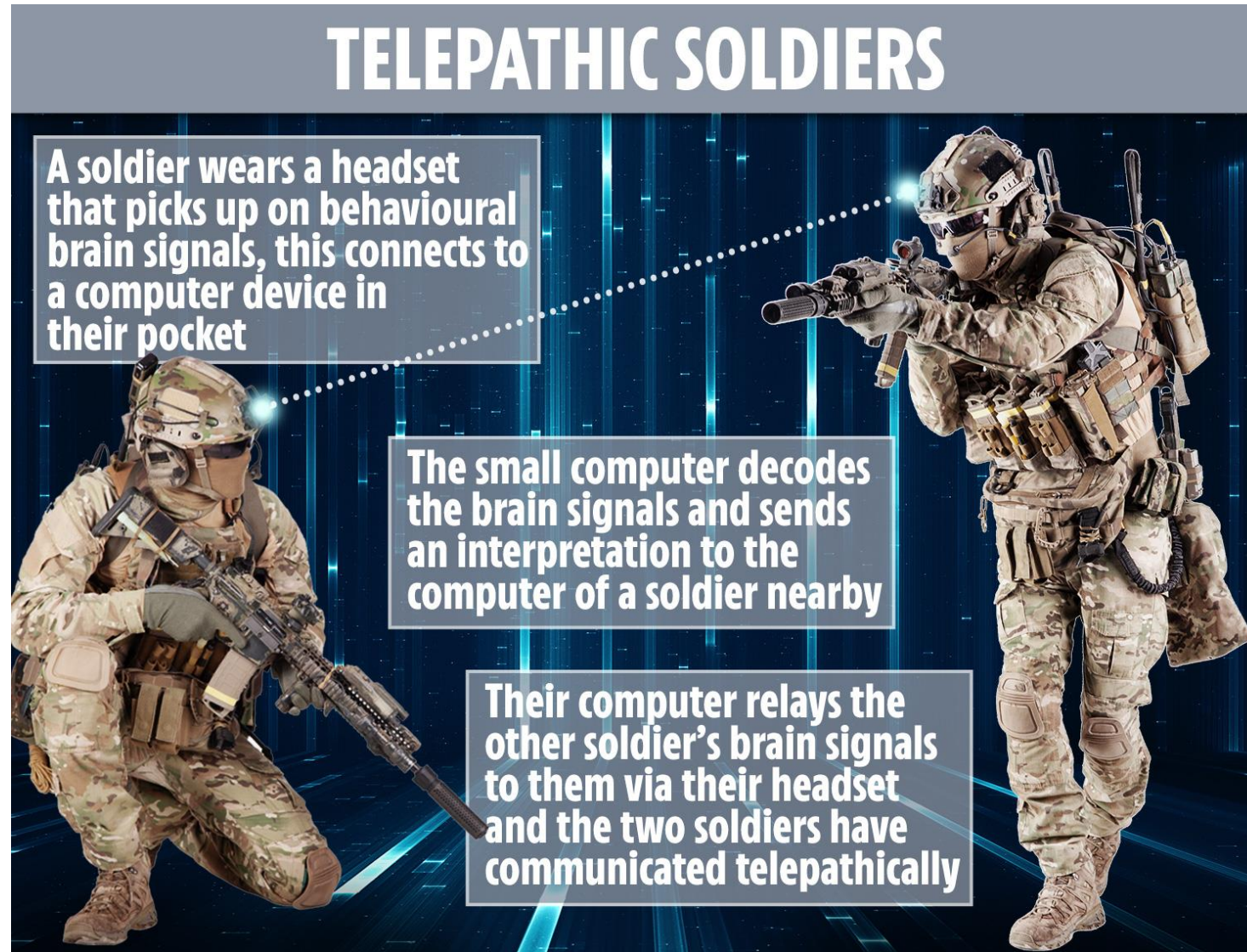
The question of respect for diversity and the definition of disabilities will also be among the questions addressed via the issue of cochlear implants for deafness or neurodevelopmental disorders on the autism spectrum..

IBC report on ethical issues of neurotechnology

Identified Risks

- **Cerebral/mental integrity and human dignity.** Because of the growing possibilities to modify the brain (structure and function), and consequently the mind, in an invasive and pervasive way.
- **Personal identity.** This refers to our ability to think and feel for ourselves, whereas neurotechnology may blur the participation of the individual-self. Thus, we need to preserve individuals' control over decision-inducing neurotechnology.
- **Freedom of thought, cognitive liberty and free will.** External tools that may interfere with our decisions can challenge an individual's free will, and consequently an individual's responsibilities. In this way, neurotechnology could affect freedom of thought, decision-making and action. Taken together, these could have a profound impact on justice systems and social organizations.

Further Possible challenges to Mental Integrity



Mental Privacy and Brain data confidentiality



Specific issues arise from brain data collected by neurotechnology:

- i) Inferences can be drawn from their analysis about **actual awareness, emotional state, tastes or even thoughts**. It is thus essential to preserve the strict confidentiality of this particular kind of data that are the brain data.
- ii) Inferences that can be drawn from brain data analysis may also enable **prediction of an individual's behaviour**. Big data analytics enable privacy-sensitive inferences to be made from non-sensitive data. Here we have identified the risk of neurosurveillance, monitoring, for example, attentional engagement or awareness at the workplace or at school.

Mental activity is the most intimate part of the human being, and should be protected against illegitimate interference.

Thus, brain data should be considered as sensitive personal data.

Some aspects of brain data are already subject to regulation: health data and personal data, at least in jurisdictions that have adopted laws such as the GDPR.

- **Distributive justice.** Neurotechnology can bring benefits for humans, particularly for neurological and mental health, but also in several other fields such as education. However, their **availability and accessibility** may also increase inequalities by conferring privileges on a few who may have access while excluding those who do not have access for economic, social, cultural, moral, religious or geographic reasons. It is thus necessary to ensure well-regulated and fair access to these technologies.
- **Discrimination/bias.** The algorithms driving most contemporary neurotechnologies, working according to an average or standard, classify the individuals from whom the data are being collected into groups, thereby reinforcing prejudices and biases that may result in discrimination and enhance vulnerability of individuals and groups.
- **Misuse.** This issue concerns unauthorized or coercive use of neurotechnology, such as a breach in cybersecurity in the case of fraudulent access to neural data. Third-party interference in device function for non-benign purposes or malicious hacking are also serious concerns.

- **Augmentation/enhancement.** There are serious ethical questions regarding how this kind of ‘enhancing neurotechnology’ can be used appropriately, given the lack of safety and efficacy, and the challenges related to human dignity, autonomy and justice.
- **Interests of the child.** It is necessary to pay special attention to the ways in which neurotechnologies could affect the brain in childhood and adolescence. At this rapidly changing and life-defining period of development of the brain, it is crucial to preserve the future rights of children and adolescents to make autonomous decisions, as well as their privacy. Special considerations and specific guidelines and regulations must be implemented when neurodevices are used in healthcare on children and adolescents, or by them for personal use such as neurogaming or neuroeducation.
- **Informed consent.** Considering the potential for changes in perception of personal identity and cognitive abilities, additional safeguards and robust, context-specific informed consent procedures must be followed in view of the nature of the technology.



9 Recommendation Principles



1. Promote responsible innovation in neurotechnology to address health challenges.



2. Prioritise assessing safety in the development and use of neurotechnology.



3. Promote the inclusivity of neurotechnology for health.



4. Foster scientific collaboration in neurotechnology innovation across countries, sectors, and disciplines.



5. Enable societal deliberation on neurotechnology.



6. Enable the capacity of oversight and advisory bodies to address novel issues in neurotechnology.



7. Safeguard personal brain data and other information gained through neurotechnology.



8. Promote cultures of stewardship and trust in neurotechnology across the public and private sector.



9. Anticipate and monitor the potential unintended use and/or misuse of neurotechnology.

IBC report on ethical issues of neurotechnology

About NeuroRights



The IBC considers that neurorights embrace certain human rights that are already recognized in national laws, international laws, international human rights instruments and other consensus documents.

These rights rest on the recognition of the basic rights of all individuals to
physical and mental integrity,
mental privacy,
freedom of thought and free will,
the right to enjoy the benefits of scientific progress,

and on the recognition of the need to protect and promote these rights with regard to the application of neurotechnology.

They also include the right to decide freely and responsibly on matters related to the use of neurotechnology, without any form of discrimination, coercion or violence.

Major recommendations by the IBC

To UNESCO and other international organizations:

- Provide new insights into the interpretation and application of existing human rights instruments by legislative bodies and courts in relation to the new challenges;
 - Propose the adaptation of existing human rights instruments and the proclamation of new human rights
 - Organize global dialogues in the field of human rights towards building a consensus on the nature and substance of neuro-rights.
 - Consider convening a multidisciplinary group of experts to develop a policy-oriented governance model, to monitor progress in the field, and to examine whether the issues raised are effectively covered by the existing legal frameworks.
-
- **On-going UN works in the framework of the 75th Charta anniversary dec 2023**

Comité
d'éthique
Inserm



Merci / Thank you.

Towards a Governance Framework for Brain Data [Marcello Ienca, Joseph J. Fins, Ralf J. Jox, Fabrice Jotterand, Silja Voeneke, Roberto Andorno, Tonio Ball, Claude Castelluccia, Ricardo Chavarriaga, Hervé Chneiweiss, Agata Ferretti, Orsolya Friedrich, Samia Hurst, Grischa Merkel, Fruzsina Molnár-Gábor, Jean-Marc Rickli, James Scheibner, Effy Vayena, Rafael Yuste & Philipp Kellmeyer](#) *Neuroethics* **volume 15**, 20 (2022)





Thank you for your attention

Contact

Herve.chneiweiss@inserm.fr