ANTICIPATE

Establishing Neuro Rights

Abstract

Brain implants already enable people with paraplegia to control robotic limbs, restore basic vision and modulate neural activity to treat diseases like Parkinson's. Over the next decade our growing ability to both read and write brain data will transform the treatment of neurodegenerative and psychiatric conditions, but it will also increasingly be used to enhance cognitive function in healthy people. This could greatly expand our ability to learn and improve ourselves. But the creation of two-way conduits into people's minds and huge pools of sensitive brain data also raise profound questions about privacy, personal agency, and the integrity of the individual. This might necessitate the establishment of a new bill of neuro rights to ensure that new technology is used properly, and its benefits are available to all.

- What are the implications for society of the development of technology in brain science?
- How can we ensure wide access to neurotechnology and prevent the formation of "cognitive elites"?
- Do we need new neuro rights or a reinterpretation of existing human rights?

Participants

Moderated by:

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With:

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Marcello Ienca, Group Leader, EPFL; Senior Research Fellow, ETHZ, Italy

Judy Illes, Professor of Neurology, University of British Columbia, Canada *(remotely)*

Jürg Lauber, Permanent Representative of Switzerland to the United Nations and other International Organizations in Geneva; Member, GESDA Diplomacy Forum, Switzerland

Highlights

Neuroscience and neurotechnology are progressing quickly, bringing profound questions that society will have to face in the realms of human rights and governance.

The driving factor in all these scientific breakthrough advances over the last two decades has been the engineering sciences, computer science and AI that have enabled new ways to read signals from the brain, said Olaf Blanke, which leads to questions about how to decode, detect, and describe all that activity. Getting access to all that neural biological data is a modern novelty. "We can also write now into the brains," said Blanke, a medical doctor whose research focuses on the neuroscientific study of multisensory body perception and its relevance for self-consciousness. "So, you have this reading out of the brain and this writing into the brain. A very important aspect is that most of the research currently done is trying to build loops, reading out and writing in, in specific synchrony, because the brain does not need the same input all the time. It needs it when I am speaking, when I am moving my arms, it needs to coordinate an orchestrated activity. These closed-loop systems, a typical engineering way of thinking, is really something that has happened over the last 10 years, I would say, in the neurotechnology and neuroscience field."

It is clear to experts in the field that people should have privacy rights towards the data extracted from their brain, regardless of whether the data entails invasive or non-invasive brain-computer interfaces (BCI). However, it is unclear what might be the best way to enforce those rights. There are four levels of governance that could be applied towards neurotechnology: self-regulation; ethical guidelines and so-called 'soft law';binding national regulations; and international human rights law. A poll of the audience at the session found 70% said they had personally anticipated some of the opportunities and risks of neuroscience and/or neurotechnology; 30% said they had not. Whether or not the UN's landmark 1948 Universal Declaration of Human Rights (UDHR) needs to be updated remains an open question worth looking into by scientific experts and diplomats together, said Jürg Lauber. That is why the idea of "neuro rights" emerged from the observation that the intimate link between the human brain function and personal identity is so important that it cannot be addressed at the normative level exclusively on ethical requirements and best practices. It also needs to involve fundamental entitlements and interests that can be construed as moral and legal rights.

"We certainly should not shy away from this [idea to update the UDHR] at this stage of the discussion. We have to look into it," said Lauber, a lawyer who was Swiss ambassador to the UN both in New York and in Geneva, and, before starting his long career as a Swiss diplomat, worked on peacekeeping missions in Namibia and the Korean Peninsula. "Which is why it is so important to have GESDA as a platform to bring those who understand the issue and those who think about the necessary governance action together to have a discussion that is very science-based, fact-based." The key to governance is to consider all sides and perspectives, he said, including asking whether the best way might be a treaty, non-binding rules or just making existing rules more accessible to countries that don't have policy frameworks to handle these emerging advances. "If we do not have common understanding, processes, we are likely to become hostage of hidden agendas, of wrong perceptions," he said. "We need to understand each other's concerns and then remain flexible, adapt the process."

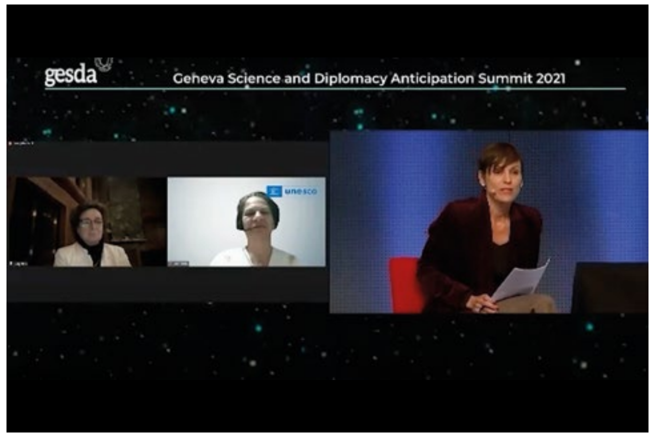
The UN education and culture agency, UNESCO, has been looking at this issue. It established the International Bioethics Committee (IBC), which issued a declaration on bioethics and human rights, and is examining whether the UDHR needs updating. The Organization for Economic Cooperation and Development (OECD), established a neurotechnology working group that released, in 2019, a recommendation on responsible innovation in neurotechnology. That set the first international standard and is designed to foster responsible innovation and to bridge the gap between neurotechnology development, society, and ethical norms. Because of the far-reaching issues involved, Lidia Brito said, it is clear that more than scientists and policymakers must be involved. "We do need society to be involved. Because we are talking about the human being," said Brito, a forest engineer who has worked with UNESCO since 2009 and served as a member of several international boards. "And that is why it is so great that we have a chance in the [GESDA] Summit to have this session," she said. "These kinds of global issues need global responses." And for that to happen, emphasized Brito and other experts, diverse opinions from all walks of like should be heard, particularly those from vulnerable populations that may become still more vulnerable if new technologies are not used ethically and for the benefit of all. “I think that is also why GESDA has chosen this topic,” she said. “Because we know that we have to anticipate.”

Using those advances in neurosciences, researchers are looking into potential powerful therapies for individuals with cognitive deficits in attention and memory. That opens questions about identity and personality, based on memory, that need examining by scientists, policymakers and civil society. Even religion could be a factor. “Will these patients who are lucky to recover a memory have an alteration of the self?” asked Blanke, drawing distinctions between this work and other areas of public health. “If you have a new vaccine or you have a new cancer therapy, you do not have this consequence on humanity or on identity itself, or at least it is an open forum for discussion.”

That has led to short-, medium-, and long-term ethical imperatives, according to Judy Illes, who pointed out that religious and spiritual leaders in Canada, including those from Indigenous communities, are engaged in this examination through the Canadian Brain Research Strategy (CBRS), which is associated with the International Brain Initiative (IBI), a collaboration between Australia, Canada, China, Europe, Japan, Korea and the United States to speed up progress on ‘cracking the brain’s code’. The short-term priority must be to focus innovation on brain diseases such as Alzheimer’s and Parkinson’s, drug-resistant paediatric epilepsy, mental illnesses such as depression and obsessive-compulsive disorder, and degenerative diseases that could be helped by neurotechnology, said Illes, a pioneer in neuroethics who focuses on ethical, legal, social and policy challenges at the intersection of the brain sciences and biomedical ethics.

Over the longer term, she said, there should be increasing focus on “questions also about invasiveness and non-invasiveness: what we put into the brain, what do we not put into the brain, but we can still modulate it. And what these concepts mean to different people; focus our attention on what are the important goals and expectations of patients and medical doctors and targets that define good and bad outcomes”. She recommended more discussion through forums like GESDA rather than pushing for new laws, though the shortcomings of tech giants like Facebook show that more self-governance “may not work”. Blanke agreed, recommending that questions of governance generally “should not split” brain data from all of the information that people reveal about themselves online “since it’s all related to brain activity and brain processes”.

Some neurotechnology companies that deal with “potentially highly sensitive” brain data are committing to responsible innovation and establishing best practices and standards to ensure the safety, efficacy, and scientific validity of the technologies they develop, said Marcello Ienca, whose research focuses on ethical, legal, social and policy implications of emerging technologies. International associations like the Institute of Electrical and Electronics Engineers (IEEE) are establishing standards for brain-computer interfaces. A second level of governance – ethical guidelines – extends to privacy, personal autonomy and respect for personal identity, and are being worked out by some organizations and academics such as the International Neuroethics Society (INS) and a working group on neuroethics within the United States’ NIH BRAIN Initiative. One of the initiators of the NIH effort, Columbia University professor Rafael Yuste’s lab, is another leader in this field. Several countries also are legislating on neurotechnology and neurorights. “The pioneering country is Chile,” said Ienca, “which has recently passed both a neuroprotection bill, which will regulate the collection and processing on brain data, and also a constitutional amendment, which will introduce certain principles such as psychological integrity in their constitution, and they are moving quite fast with this.”



Other nations such as Brazil, France and Spain are passing laws on bioethics and neurotechnology, while Italy has been working on it from a data protection perspective. Internationally, the Council of Europe has launched a five-year strategic plan on human rights in biomedicine. “It’s very unlikely that a one-size-fits-all approach to governance will be effective,” Ienca said. “In fact, what we are seeing emerging internationally is what can be called a multilateral governance framework.” Which is why forums like GESDA and anticipatory ethics are important, Ienca added, because it would be valuable to consider regulating not a specific category of data, like a neurological measurement, but more around function. “If we can make privacy-sensitive inferences about people’s mental states, without their authorization, that’s probably what we need to regulate,” he said.

Takeaway Messages

Over the last two decades, the driving factors in neuroscience and neurotechnology have been the engineering sciences, computer science and AI that enabled new ways to read brain signals.

“Neuro rights” are the moral and legal rights to protect the human brain.

Four levels of governance could be applied towards neurotechnology: self-regulation; ethical guidelines and so-called soft law; binding national regulations; and international human rights law.

Given the novelties of neurotechnologies, emerging governance frameworks are subject to the same novelties, making it a rapidly dynamically evolving scenario.

Because of the complexity of the ethical challenges, a one-size-fits-all approach to governance will likely not be effective; a multilateral governance framework will probably offer the best solution.

It is clear that the involvement of scientists and policymakers is not enough; the voices of citizens also need to be heard because of the profound implications.

More information

Session recording on YouTube

Related interviews: Nadia Isler, Olaf Blanke, Marcello Ienca

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