

Negotiating the Boundaries of Being Human

by Cynthia Weber

By 2029, industry experts predict that there will be more than one million people around the world with implantable brain interfaces. — I Am Human

Are there non-negotiable boundaries to what we consider “being human”? Will our efforts to enhance our current abilities or regain lost abilities with the aid of technology—for example, motor or cognitive loss after disease or injury—eventually change those boundaries and alter our understanding of what it means to be human? Questions such as these served as the background for a lively panel discussion and selected screening of the award-winning documentary film, *I Am Human*, held in December 2020. The event was a collaboration between IEEE Brain and the [International Neuroethics Society](#) (INS) and featured distinguished panelists from the areas of neurotechnology, neuro-activism, and neuroethics. Introduced by Laura Cabrera, Assistant Professor of Neuroethics at Michigan State University and Chair of the IEEE Brain Neuroethics Subcommittee, and moderated by Joseph J. Fins, President-Elect of INS and Professor of Medical Ethics and Chief of the Division of Medical Ethics at Weill Cornell Medical College, the online event drew more than 260 viewers to hear debate on key points raised in the film regarding the future role of neurotechnology in society.

Panel participants for the event included Nita Farahany, President of INS, Founding Director of Duke Science and Society, and Professor of Law and Philosophy at Duke Law School—who also appears in the film; Jennifer French, Founder and Director of [Neurotech Network](#) and advocate for end user rights; and Jacob Robinson, Co-Chair of IEEE Brain and Associate Professor of Bioengineering and Electrical and Computer Engineering at Rice University.

The film highlights diverse neurotechnology research areas at different stages in the development process, from deep brain stimulation (DBS), which is becoming standard of care for treatment of Parkinson’s disease, to [BrainGate](#), an evolving brain-computer interface (BCI) system for muscle activation with the goal of achieving movement restoration, which is still at the volunteer participation level. These particular technologies, along with a visual prosthesis (also at the experimental stage), are explored through the stories of actual end users. In addition, the film delves into potential commercialization of non-medical BCI technologies through direct-to-consumer devices. As David Eagleman, noted author and neuroscientist, states in the film, “our technology right now is about helping people with diseases ... but it’s this exact same technology that will allow us to expand ourselves, expand our reality, expand our senses, [and] expand what we can do with our bodies.”

It is this tension between the development of neurotechnology for medical applications and those technologies designed primarily for consumer use, e.g., general wellness and enhancement, that further underscores the need for a focus on safety and ethics as well as access, concepts explored both in the film and during the special event. Looking to the future of medical and consumer neurotechnologies, “if companies that are well-resourced develop

technologies, even though they might be geared toward a consumer market, those technologies can then in turn be used for biomedical devices,” says Jacob Robinson. “So in some sense there is an inherent public/private partnership. These are shared technologies taken out of the lab into a commercial space and out of the commercial space and back into the lab. I think there is an opportunity there that we should be open to.”

The pioneers

Bill, the BrainGate participant profiled in the film, talks about his willingness to be part of this research effort. “Somebody has to do research, or no breakthroughs are going to happen. And even if I don’t get any benefit out of this, eventually somebody’s going to benefit from what I’m doing,” he states. “Like most people, I thought quadriplegics all were stuck in bed, they didn’t do anything ... but now I’m learning that’s not really true.”

For Anne, who weighed the decision of whether or not to proceed with the invasive DBS procedure, it came down to accepting the unknown, recognizing that in either case, her decision would impact not only herself but her family. “When it affects so many people, I think you have a duty to try what is reasonable,” she says. Ultimately deciding to go through with the surgery, she states, “It was an extreme procedure. It was not for the faint of heart.”

“In this film, they depicted the decisions that people were making as they were putting their bodies forward for science and those people are truly pioneers in the medical field,” says Jennifer French. “We don’t always think about the frontline people who are accepting these technologies.” Even as the film pulls us into the users’ personal stories, it perhaps does not do a good enough job of conveying the actual risks associated with neurotechnology use and implantation. However, “the hope is that next generation devices will be successful with even less risk, and so perhaps the decisions will become easier,” Robinson adds. “The benefits would remain the same but the potential side effects or the invasiveness of the procedure would become mitigated.”

French also supports the idea that research studies need to focus on not only what has worked well, but what has not. Everyone is excited by encouraging results and good days in the lab, but “we should also document failures and adverse events so that we can learn from them,” she says. In addition, many times the user can help troubleshoot the problem, and therefore should be considered more along the lines of a “joint research fellow” rather than as a study subject. “When we take development out of the lab, we learn so much more,” she adds, and that begins with collaboration and inclusion. In fact, a 2015 survey of neurotechnology end users highlighted the fact that they want to be involved at the level of the initial research idea. “We need to more actively include the end user in the development process,” French says. “This is part of where we fail in medical devices.”

Nita Farahany also echoed the importance of user consent and productive conversations exploring the risks and benefits of any procedures. Currently, most neurotechnology solutions are implemented late in the disease and/or disability cycle after other treatments have failed,

in part as a last resort, but also “because we are still in the early days of development,” she adds. Long-term issues such as upgrades to devices and explanations have not yet been clearly articulated for most devices. “We need to determine how to best safeguard participants in this essential research,” Farahany says.

In addition, there needs to be consideration of ways we can support these participants throughout their lifetime, regardless of device success or failure. “We all benefit from progress in these areas, and we should care for those who put their lives at stake for the improvement of technology,” Farahany says. The creation of public or private trust funds for these experimental users might be one approach. As Joseph Fins states, “even as we do big science, we need to make sure participants have basic medical care.”

Questioning the path

Even as knowledge and technology improves—due in part to the active participation of pioneers—there is still a long way to go before we understand and crack the code that powers the brain and nervous system. Still, as Bryan Johnson, Kernel Founder and CEO, says in the film, “We are about to enter into the most consequential revolution in the history of the human race, where we can take control of our cognitive revolution.” Although acknowledging the potential benefits associated with this revolution, Johnson is restrained in his enthusiasm. “I’m very concerned about who makes breakthroughs in neuroscience. As a society, it’s important we be ready for this,” he says. “How can we be thoughtful about how we build these technologies?” And, as one engineer noted in the film, how do we plan mitigation for all the things that can go wrong on a mass scale that we cannot foresee?

In the panel discussion, French explains that a lot of current technologies have their roots within the medical field, and in that field, “we are constantly thinking about risk versus benefit,” but when we start to go towards augmentation, for example, and move out of the medical field, we may not be thinking about risk as much as we should. She reiterates that we need to remain cautious and carefully examine the motivations for neurotechnology development. French adds that the film hints at this idea of a ‘broken brain’ that can be fixed by technology, but we should be wary of someone else’s visions of a “perfect human.”

As commercial companies move into marketing neurotechnology devices with promises of cognitive enhancement, mind-reading capabilities, and other abilities that move beyond what humans have traditionally been capable of, it may be important to consider what lies ahead in terms of control and ownership. Regardless of whether the technology is for medical or non-medical use, understanding its potential impact requires community conversations that expand to include those outside our domains. Scientists, engineers, users, and ethicists have the option to embrace this opportunity to negotiate boundaries while the field is still evolving.

Ultimately, “there is great benefit to these technologies but there are also risks,” Farahany states to a room of students in the film. “Who has access to these devices? Who gets to drive and change these devices? Whether it’s hackers, corporations, governments, other people ...

what protections, if any, exist within society today? It's arriving and unless we start deciding today what protections you want for your brain, it may be too late." She adds, "We are fundamentally about to change what it is to be human, and if so, are we okay with that?"

More information about the event can be found [here](#).