Neuroethics for a Versatile Future

Neural implants are becoming an increasingly common medical intervention to treat neurological disorders. Currently, this type of implant is being used to treat people with Parkinson's disease and multiple sclerosis. In these cases, the implant is made of several long "electrode" rods that go deep into the brain and stimulate the part of the brain that uses fine motor skills in order to treat the diseases' motor problems. Another very common implant is used in prosthetics and prosthetic limbs to better assist with communication between body tissue and the device.

How common are these devices? Currently, around 160,000 people[1] globally are using deep brain implants. In addition, that number is rising as new evidence of the efficacy of these implants emerges. Public and private sector entities are currently researching and developing implants that can enhance night vision for military applications, use deep brain electrical impulses to revive forgotten memories, cure depression and similar mental health issues, and potentially download new information to the brain.

While these implants can do a lot for people, and are most commonly used to stimulate parts of the brain to help a person do something that they would not be able to do without the implant, these technologies also collect massive amounts of data. For example, a current device that treats multiple sclerosis called "Activa PC+S DBS system," currently collects background brain data while treating multiple sclerosis and makes that data available to researchers. In the near future, researchers envision linking these implants to other devices. That long range plan, where data can be shared among devices leads us to think about data ownership and control.

Who can control the data being captured by these sensors? Should the company who created the sensor and affiliated researchers have access to all of the brain signal data coming from the device? As these technologies arise, we need to create new ethical and legal guidelines. If we are able to have the device monitor and influence certain brain functions, we want it to do what it was meant to do and not do other potentially harmful or illegal things.

I think one of the most important questions pertaining to the neuroethics of sensors is, who can control and use the data and for what purposes. In the U.S. and the E.U., the starting assumption is that the person for whom the implant is being used owns and controls his/her data. But in order for researchers to collect data, these two entities rely on a concept called informed consent. Under that concept, conventionally, when medical and personal data is collected, there are laws that govern the collection and use of the data. The laws require that entities wishing to use the data for research purposes, must inform patients and obtain their consent before collecting and using patient data and must explain upfront what they will do with the data. Currently, the most common l aw i n the U.S. governing the use and collection of medical data is HIPAA which is a law that requires entities which collect medical data to inform and ask for consent from the patient first. This is the current way privacy of patient medical data is handled.

Now that there is a high probability of these sensors communicating data with outside devices, we should be concerned that patients' brain data can be shared with non-medical entities. An example of this is a home virtual assistant who can take this data and share it with the company who manufactures the device. It is very possible that these entities may not inform patients what they will do with their data from these implants. In that scenario, it will be important for patients to have discrete control over their implant data.

I believe the best way to handle this problem is to implement a nationwide system of data control that relies on the logic behind blockchain technologies. This nationwide system would allow the patient to control the collection and transfer of his/her data. With blockchain approaches, the patient will have more discrete control over which data is publicly shared. This would allow the patient to choose the non-medical entities with which they would like to share their data. So, if a public or private sector entity wants to use patient implant data for purposes other than research, those entities would have to come through blockchain to ask patients' permission. Because blockchain technology incorporates monitoring and verification, this type of control prevents companies from collecting and using the patients' data without their permission. Also if the patient wants and feels that there is something not right, they can immediately pull their data away from any public/private entity or party that is involved.

Currently, patients have very little control over the secondary use of their data. This is because large data aggregators such as IBM and Oracle control the vast volumes of patient data that are used by researchers. In this context, blockchain approaches could give patients maximum control over their privacy and data and as a bonus, patients would be able to share their data with third parties and potentially make money from sharing their data. This sharing ability also allows patients to collaborate with other patients and doctors to try and speed up the recovery process and find new solutions and share patient experiences. I think with the combination of security, versatility, and advanced tech, blockchain is a one-for-all system that can be tailored to everyone's needs as we address the emerging question of neural implant data collection and control.

With all of this new technology for healthcare, many new questions and lessons will arise and it will take some time for the implant system to be a perfect and safe option for patients. But, based on my assessment, I would like to try to speed up the process a bit. I believe that through a blockchain-like method and with federal guidelines, this tech can be a very easy and safe tool to use for control of data associated with different brain problems and illnesses.

<u>Sources</u>

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