ELSEVIER

Contents lists available at ScienceDirect

Brain Stimulation

journal homepage: www.journals.elsevier.com/brain-stimulation





How I became myself after merging with a computer: Does human-machine symbiosis raise human rights issues?

Frederic Gilbert ^{a,*}, Marcello Ienca ^{b,c}, Mark Cook ^{d,e}

- a EthicsLab, Philosophy & Gender Studies, School of Humanities, College of Arts, Law and Education, University of Tasmania, Australia
- b Institute for Ethics and History of Medicine, School of Medicine Technische Universität München (TUM), Ismaninger Str. 22, 81675, München, Germany
- ^c Intelligent Systems Ethics Group, College of Humanities (CDH), Swiss Federal Institute of Technology in Lausanne (EPFL), Switzerland
- ^d Division Engineering and IT Biomedical Engineering, University of Melbourne, Australia
- e The Sir John Eccles Chair of Medicine, Director of Clinical Neurosciences, St. Vincent's Hospital, Melbourne, Australia

ARTICLE INFO

Keywords: AI Brain-computer interfaces Data Explantation Implantation Human right Neuro-right

ABSTRACT

Novel usages of brain stimulation combined with artificially intelligent (AI) systems promise to address a large range of diseases. These new conjoined technologies, such as brain-computer interfaces (BCI), are increasingly used in experimental and clinical settings to predict and alleviate symptoms of various neurological and psychiatric disorders. Due to their reliance on AI algorithms for feature extraction and classification, these BCI systems enable a novel, unprecedented, and direct connection between human cognition and artificial information processing. In this paper, we present the results of a study that investigates the phenomenology of human-machine symbiosis during a first-in-human experimental BCI trial designed to predict epileptic seizures. We employed qualitative semi-structured interviews to collect user experience data from a participant over a six-years period. We report on a clinical case where a specific embodied phenomenology emerged: namely, after BCI implantation, the patient reported experiences of increased agential capacity and continuity; and after device explantation, the patient reported persistent traumatic harms linked to agential discontinuity. To our knowledge, this is the first reported clinical case of a patient experiencing persistent agential discontinuity due to BCI explantation and potential evidence of an infringement on patient right, where the implanted person was robbed of her *de novo* agential capacities when the device was removed.

1. Introduction

Medical brain-computer interfaces (BCI) are systems that capture quantitative neural data and convert these data into various responses (e.g. therapeutic, diagnostics, preventive, etc). For instance, a patient specific algorithm can be created following quantitative data collection phases, during which intracranial electroencephalograms—internal recording of neural activities via subdural grid electrodes—are performed for assessments of an individual case of epilepsy [1]. As such, a BCI may be used to predict epileptic seizure by monitoring neural data and discharging electric stimulation, or by alerting the user when the system identifies a specific quantitative neural data threshold. In the first scenario, users are out-of-the-decisional-loop, meaning they do not get to choose whether a therapeutic response (e.g., electric stimulation by Neuropace devices) is discharged – they passively receive the stimulation. In the second scenario, users are in-the-decisional-loop,

meaning that they have got opportunities to choose whether a therapeutic response should be executed (e.g., advisory devices such as Neurovista).

Most of the ethical debates about the putative effects of implantable neural device, such as Deep Brain Stimulation (DBS) on users' personality, identity, agency, autonomy, authenticity, and self relate to the first scenario, the subjective experience of being passively out of the decisional loop [2–4]. While some studies describe neuropsychiatric DBS-induced outcomes [5,6], other reported that postoperative self-estrangement is associated with a sense of losing control and a distorted perception of one's capacities [7].

In the ethical literature, the second scenario —being active in the decisional loop— has been described as encompassing a stronger degree of autonomy: "if the subject is in the loop, she retains some autonomy over decision-making" [8]. However, despite the rapid progress of neural data collection for therapeutic purposes [9], evidence and

E-mail address: Frederic.Gilbert@utas.edu.au (F. Gilbert).

^{*} Corresponding author.

literature about the impact of these monitoring devices on the patient's subjective experience of being in-the-loop is lagging [10]. This current study not only look at whether implanting and using a BCI may induced postoperative personality changes, importantly examines whether explanting BCI may lead to similar neuropsychiatric effects.

We report on the case of one patient (Patient R) implanted with a BCI that was designed to keep her in the decisional loop by detecting epileptic seizures through brain data collection. Postoperatively, Patient R experienced a robust sense of empowerment, embodiment, mergence, de novo agential capacities which appeared inseparable from functioning with her implanted device. Yet, when the device manufacturer forced her to undergo device explantation, she suffered substantial harms to her de novo self-concept. In particular, Patient R experienced radical psychological discontinuation and disruption of agential capacities, which continue to cause persistent emotional and affective harms years after system operator removal. The case of Patient R raises critical ethical and legal questions: what moral and legal rights are BCI-implanted individuals entitled to as patients? Are we in front of new fundamental rights issue, —specific to the cerebral, mental, and agential domain, hence called "neurorights"?

In the past years, there have been suggestions to recognize novel human rights or to expand existing legal rights to address evolving neurotechnologies [11–15]. Although there are strong reasons to be agnostic [16] or even sceptical [17,18] on whether neurorights are needed, we analyse how qualitative data from a clinical case could be potential empirical evidence corroborating the thesis that some user's rights, may be needed to preserve, promote, and protect a person's *de novo* agential capacities.

2. Methods

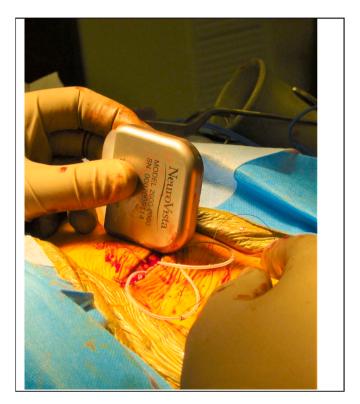
During a period of 6 years, we examined perceptions of self-change as articulated by Patient R, who volunteered to be enrolled in the first in-human experimental trial testing a personal advisory implantable brain device for predicting epileptic seizures via neural data recordings (See Images 1 and 2). Full medical details of the trial and system can be read here [1,19].

Patient R was diagnosed with severe chronic epilepsy at 3 years of age, which had a profound detrimental impact on her quality of life. Despite undergoing a wide range of treatments over the years, none were successful in managing her condition effectively. By the time she reached her late 40s, Patient R underwent a surgical procedure to implant a Neurovista BCI, which could detect and alerting her to the onset of seizures. This enabled her to take prophylactic medication such as clonazepam to prevent seizures from occurring. Remarkably, Patient R went from experiencing an average of three seizures per month to none, thanks to the efficacy of the BCI device. Unfortunately, the Neurovista trial was discontinued due to financial constraints, necessitating the explantation of the device from Patient R.

At non-standardised intervals, ¹ Patient R was asked a series of openended questions intended to elicit first-person narratives of subjective perceptions of changes to her sense of self (interviewed conducted and writing data collected by FG). To reach an understanding of patient's inner experience with BCI, we apply a qualitative research design. We



Images 1. Implantation of silicon lead assemblies on cortical surface via craniotomy. Silicon lead assemblies contained eight contacts collecting intracranial electroencephalograms data through the telemetry unit. (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article.)



Images 2. Insertion of the telemetry unit in subclavicularly area. Telemetry unit automatically measured and wirelessly transmitted patient's brain data to external personal advisory device.

¹ Patient 1 was enrolled in "(H0013883) Implantable Seizure Advisory Brain Devices: Ethical Implications" study. Patient R was interviewed in English by FG (lead author), along with other Neurovista users (see 17). However, the unique narrative of Patient R led to subsequent and separate follow up interviews by FG over a period of 6 years, at non-standardised intervals which required the ethics approval of H0013883 to be extended twice. Patient R had been explanted during all interviews. The initial interview was conducted at the home of Patient R, all subsequent interviews were conducted over phone and emails, except one handwritten correspondence. FG conducted the analysis of the data collected from the interviews and identified themes within the data.

used a qualitative instrument grounded in phenomenology to conduct in-depth and semi-structured interviews. Interviews were based on an adapted version of the qualitative tool first developed and tested in Ref. [20] and further elaborated in Refs. [7,21,22]. Qualitative data were collected from interviews and correspondences over the period of our project. Questions were followed up at various intervals to check the content of the answers, and to observe any persistence in the narratives. Interviews were transcribed verbatim. Contents were then manually coded and finally analysed by regrouping the patient's subjective experiences into common themes and clusters.

Our qualitative methodology allowed us to capture singular, unique, first-person perspectives that are not identifiable with standardized questionnaires and scales. By looking at the subjective character specific to the patient's experience of being implanted with a brain device run with a data-driven algorithm, we believe we can gain better empirical and conceptual understanding of the phenomenology of potential BCI-induced benefits and vulnerabilities.

3. Results

Patient R's narratives were analysed and categorised into two groups of experiences: feelings generated by 'being-implanted', and feelings generated by 'being-explanted'. Both groups of experiences were subdivided into eight clusters of first-person experiences. These eight clusters were populated by the patient's key answers and quotes. Our study identified the following experiences of Patient R:

A) Being-implanted

(A.1) Feelings of adjustment with BCI.

Experiences ranging from initial excitement to challenges in adapting to new ways of interacting/living with technology:

"They had to read my brain and get to know me. The [BCI] had to get to know me. And everything that affected me. So everything from small seizure activity that occurs in your brain from a migraine occurs in your brain; all those different things cause different readouts."

(A.2) Feelings of embodiment with BCI.

Experiences described as becoming seamlessly integrated into her sense of self and everyday life, leading to personal growth and a feeling of transformation as the technology became a part of who she is:

"[The BCI] was like an alien at first, you grow gradually into it and get used to it, so it then becomes a part of everyday, [...] it becomes part of you. Because that's what it did, it was me, it became me, [...] with this device I found myself [...] It changed who that person was then and I found myself changing ... growing I suppose [...]."

(A.3) Feelings of empowerment with BCI.

Experiences described as an increased sense of independence, leading to a heightened sense of agency and control over her environment and abilities through the technology:

"I felt like I could do anything-I can do this-I can do everything I want to do-apart from obvious little things like jobs or things like that I can't do a lot of things. But I could do-I could drive, I could see people, I was more capable of making good decisions-not bad decisions."

"I feel like-I wish I could've been a better mother-I know I was a good mother under the circumstances-but I reckon I could've been ever better [had I been implanted with the BCI earlier]. [...] I blame myself that maybe my kids haven't gone and done things that they wanted to do, so I blame myself still."

(A.4) Feelings of symbiotic agency with the BCI.

Experiences reported as mutually beneficial relationship between her and the technology in which they operate together to achieve a common goal, with each entity contributing its unique strengths and capabilities to enhance the overall performance of the symbiotic agency:

"My device became as dependable as time itself. Your alarm clock that wakes you up in the morning to get you to work on time! Your appointments for that day! Checking the weather forecast. To decide what to wear! If you can go for a walk, to the beach or a picnic etc. We use mobile phones every day, we rely on them all the time. People are attached to these things more than they realise and think nothing of it! Why then would it be so strange for me, myself to become so attached to [the] device and feel that we became one and I felt safe and secure? Why then should I not mourn the loss of something that gave me the most secure feeling I could ever have imagined?"

B) Being-explanted

(B.1) Feelings of resistance to explantation of the BCI.

Experiences described as a reluctance to lose the BCI, which was an integral part of her identity and daily life:

"I wish I could've kept it-I would've done anything to keep it. [...] I wanted to stay with it [...] I would've done anything-I would've paid money-I would've done anything if I could've."

"I was the last person to have the device out."

"G (husband) even said he would do anything so I could keep it. [...] Buy it even. He would have taken a second mortgage on our home for me to keep it."

(B.2) Lost feelings of symbiotic agency with the BCI.

Experiences described as a loss of control over the mutually beneficial abilities between her and the technology, resulting in emotional pain and psychological insecurity:

"We had been surgically introduced and bonded instantly. With the help of science and technicians we became one. We did together what was expected of us! We performed beautifully ... To this date, I have never again felt as safe and secure. Nor am I the happy, outgoing, confident woman I was. I still get emotional thinking and talking about my device, and I miss terribly having the security of it."

(B.3) Feelings of cognitive and psychological uncertainty.

Experiences described as a sense of confusion, disorientation, and anxiety as she navigates a new normal without the technology that had become an integral part of her cognitive and emotional processes:

"I'm missing and it's missing. Cause I felt insecure, because [I] can't think straight [...] I'm not sure anymore and I'm scared that I'm

panicking too much now whereas before there wasn't that question, it was right there, I knew it and now I'm frightened that I might be making wrong decisions because I don't have that back-up; that part of me is gone. So I do miss it and I'd do anything in the world and I said to [Neurovista] 'when's the next [BCI]?'"

(B.4) Feelings of loss and stolen identity from having the BCI taken away.

Experiences described as a sense of overwhelming sadness, powerlessness, and loss of self, as the technology that had become an extension of her identity is no longer present:

"They took away that part of me that I could rely on and I got scars [...] I cried, I did a lot of crying, I could still do a lot of crying but now I'm left with like little craters in my head from where they cut big holes or big craters [...] that upsets me because that made me a different person [...] I had my device-I was self-assured [...] I wish I hadn't of gotten it taken out."

"It was so overwhelming for me I became emotional and cried. [...] Living without my device was very hard at first. I always felt like there was something missing, I'd forgotten or left behind ... a part of me! [...] My confidence in myself was shattered. Doubting every feeling. Asking or questioning myself all the time. [...] Am I safe? [...] How will [I] cope and live without my trustworthy dependable part of myself? [...] Staying home alone is scary. [...] I do not go out much unless I'm with my husband. My social life is not existent now."

(B.5) Feelings of a profound loss:

Experiences described as a deep sense of grief and mourning for the loss of the technology that had become an integral part of her life and identity:

"A mourning. I mean I know it's been a while, but I still know what it did and how it worked and in a way if you think about it you can feel it still. It's like it's there but it's not there. You can remember everything about and I mean it taught me, it taught my doctors more about me and more about how to read things."

"To finally switch off my device was the beginning of a mourning period for me. A loss, a feeling like I'd lost something precious and dear to me, that could never be replaced: It was a part of me."

4. Discussion

4.1. BCI and self-understanding

Patient R presents evidence of how the experience of having a BCI that constantly monitors, processes, and translates one's brain data to make predictions may radically impact the implanted patient's self-understanding and self-concept [23]. Did the BCI become part of her personhood [24,25]? Patient R reported that "[the BCI] becomes part of you. Because that's what it did, it was me, it became me". The data disclosed and exposed by the device were incorporated into Patient R's self-conception and self-understanding, which resulted in a reported *de novo* identity: "that made me a different person". Based on Patient R's narratives, it seems that she merged with the technology in that her postoperative subjective experiences embodied a new revision of her self-understanding: "we became one"; "with this device I found myself".

With constant feedback from the BCI, Patient R received alerts from the device, then used this information to decide whether to self-

administer medication to prevent seizures. As Patient R recounts: "[The BCI] changed who that person was then and I found myself changing". In effect, the BCI allowed her to exercise her autonomy by giving her the capacity to better control the number and severity of her seizures.

Our team observed salient phenomenological effects of being in-theloop. The BCI played a critical role in Patient R's decision-making processes to the extent that the technology was inextricably present in the daily decisions she had to make: "I had my device-I was self-assured", "I felt like I could do anything-I can do this-I can do everything I want to do [...] I was more capable of making good decisions". Initially, Patient R retained autonomy in deciding whether to follow the advice of the implanted device. As she realised just how accurate the data predictions of the BCI were, she stopped "listening" to her own instincts, and instead ceded her decision-making capacities to the technology. As such, she learnt how to let the predictive functionalities instigate her decision, how to be in-the-loop, but also of-the-loop. Her choices, in some important ways, became an epiphenomenon of-the-loop by continually outsourcing her decision-making process to the BCI. This opportunity to defer her choices to an AI system led to some novel agential abilities. These of-the-loop abilities involved, at least in part, the possession and capacity to deploy a range of competencies relating to self-discovery, self-definition, and self-direction [26]. Doing so meant that she could act in accordance with her own values while remaining in the loop.

4.2. What is a symbiotic agent?

The term symbiosis come from the field of ecology; it means two entities co-existing in a mutually beneficial relationship [27,28]. The BCI's personalised algorithm generated a unique neuronal signature. The BCI reached an optimal function by learning from monitoring Patient R's brain activities: "The [BCI] had to get to know me." In turn, Patient R perceived herself to have learned from the BCI: "it taught me, it taught my doctors more about me and more about how to read things." A symbiosis emerges when both entities augmented each other's capacities. The AI-driven personalised algorithm directly benefited from monitoring Patient R's brain activities by enhancing its autonomous predictive performance via ongoing interactions. In contrast, despite the algorithm being tailored to the specifics of each implanted patient, this device proved not to be optimally predictive across all other implanted patients in the experimental trial [1,19,22]. Nonetheless, Patient R agential capacities were augmented due to constant accurate predictive function of the BCI, which increased her confidence and abilities - her of-the-loop abilities.

Subjective postoperative experiences of Patient R amount to significant evidence of human-machine symbiosis. The onset of new and persistent agential capacities which were recounted and embraced by the patient following implantation is evidence that a *de novo* subjective experience of agency has emerged post implantation. Patient R experienced an involuntary shift in her feelings of agency, wherein radically merging with the technology profoundly shaped her agential capacities. Being-in-the-world implanted had ostensibly deep merging effects where interfacing with the neural device led to novel agential continuity.

These feelings of symbiosis were quintessential for Patient R. Upon receiving a termination order from the device manufacturer for reasons of bankruptcy, she tried to elude the situation. She expressed her strong desire to continue with the BCI and actively engaged in planned negociations, displaying elements of resistance while ultimately coming to terms with the situation: "I wanted to stay with it [...] I would've done anything-I would've paid money-I would've done anything if I could've and until today". From her first-person perspective, there was more at stake than a simple removal of a device from her brain. Being forced to endure removal of the BCI meant for her the experience of drastic agential and psychological discontinuation — a disruptive intrusion and a severe rupture of her subjective phenomenal experience of being-in-

the-world as a merged person. In sum, it robbed her of the new person she had become with the technology. She felt out *of-the-loop* and reported painful feelings of being lost: "A mourning" ... "I'm missing and it's missing" ... "They took away that part of me that I could rely on" ... "that part of me is gone". Explanting her removed a central component she relied on to be-in-the-world as a fully autonomous agent.

Following the above, a symbiotic relation appears to involve an existential dependency. The idea of existential dependency means that the existence of one particular agent or entity can somehow be dependent on the existence of some other agent or entity; accordingly, if the of-the-loop agential capacities did not exist, Patient R would necessarily fail to exist also. The contentious idea here is that Patient R would not necessarily fail to exist if her agential capacities did so because she would just fail to be an agent with these capacities (out-of-the-loop), which in the long-term temper on the probability for Patient R to exist as a *de novo* agent.

Important ethical questions are raised in the case of this patient. What are the possible moral rights and legal protections for allowing implanted BCI users to retain access to the therapeutic benefits available only through sustained and secure use of the device? Do companies or medical teams have a moral obligation to maintain any postoperative 'new person' emerging from a successful implantation of an AI brain device? Should a postoperative symbiotic person be a legal agent bearing rights and be recognised by our legal system? If a symbiotic agent is granted legal personhood, should they become subject of the law and exist in our normative legal spheres as an actor holding inalienable rights? It would be hard to see how they would not be a subject of the law (bearing and assuming their responsibilities, requiring legal protections). However, in our case above, the concept of a postoperative de novo (symbiotic) person seems to be regarded as being less than a full legal person since the device company did not prioritize her preservation and dismissed the objections and resistance of Patient R to be explanted. One relevant ethical question is whether this should have been the case.

4.3. Neuro-rights?

What rights may a *de novo* person emerging from a BCI usage be entitled to Ref. [29]? There have been calls to implement and discuss various forms of neurorights ([11–15,30]. Given the level of integration of the BCI into the patient's cognitive architecture, first, let us look at how explanting the BCI may constitute an infringement of the patient's rights to psychological continuity and mental integrity.

The right to psychological continuity, which is grounded on the psychological-continuity account of personal identity [31], has been described as the right to preserve "people's personal identity and the continuity of their mental life from unconsented external alteration by parties" [11]. Besides protecting patients autonomy-circumventing practices such as unauthorized neuromodulation, the right to psychological continuity also offers solid normative ground to protect people from the explantation of BCIs that play a constitutive role in determining personhood; i.e. the status of being an individual person, and personal identity, i.e. the attitude to identify with an individual person. Psychological continuity theories of personal identity define personal identity in terms of overlapping chains of connections between mental states (e.g. memories and affective states). Whenever the BCI enables appropriately caused mental states that play a constitutive role in determining someone's agency and personal identity, then removing the BCI may constitute a violation of her right to psychological continuity (unless the explantation is deemed medically necessary).

By affecting a person's psychological continuity, disrupting or explanting someone's BCI may thereby also cause an infringement on their right to mental integrity. The right to mental integrity is protected under the EU's Charter of Fundamental Rights (CFR), whose Article 3 states that "everyone has the right to respect for his or her physical and

mental integrity". Authors have proposed neuro-specific interpretations of the right to mental integrity. For example, Ienca and Andorno defined the neuroright to mental integrity as people's right to be protected from illicit and harmful manipulations of their mental activity, while Lavazza defined it as "the individual's mastery of his mental states and his brain data so that, without his consent, no one can read, spread, or alter such states and data in order to condition the individual in any way" [32]. According to Lavazza's definition, only non-consensual uses of the implanted BCI (e.g., non-consensual explantation, disruption of function, or functional modification) would constitute a violation of mental integrity. According to Ienca and Andorno's formulation, in contrast, consented uses may nonetheless infringe on the right to mental integrity as long as they produce disproportionate harm to the person. For example, if a BCI manufacturer goes bankrupt and requires all patients using their manufactured device to sign a consent form in which they consent to explantation, such consent may be considered invalid if the explantation results in physical and psychological harm to the user. The case above appears to demonstrate various degrees of post-trial harms. Is the loss of capacities, more precisely agential capacities affecting quality of life, a potential ground for neuroright?

4.4. Loss of de novo agential capacities as evidence of user's rights?

Is there a right to preserve agential capacities induced by a BCI because sudden removal of these capacities may lead to long terms psychological harms? To our knowledge, the clinical case above may illustrate the first published evidence of specific infringements of a patient's possible neurorights, where the implanted person was robbed of her *de novo* agential capacities with the removal of a BCI which led to diminishing of quality of life and psychological distress.

As the BCI became integrated into the patient's cognitive architecture, the boundary between the patient's pre-implantation set of agential capacities and the post-implantation agential capacities enabled by the BCI becomes blurry. By profoundly challenging Patient R's understanding of who she was, interfacing with neural device redefined the very relation she had with her own agential capacities. The capacities for *de novo* agential continuity seem to encompass a claim to the right to exercise these agential capacities. We believe the concept of agential capacities is useful —as seen across this study— to shed further light on the notion of possible neurorights.

It is hard to respect the dignity of a person unless we respect them as holding fundamental capacities for agency. Grounding human rights in human agency and autonomy has had strong advocates in recent decades [33]. Many scholars have argued that human rights are designed to protect agency [34]. Denying the value of achievable agency may not be an alternative for a human being; having a life requires indispensable conditions of agency as necessary goods [33,35,36]. Our understanding is that the UN Universal Declaration of Human Rights [37] is largely built on the notion of agency. For instance, Article 18 indicates humans have rights to freedom of thought and conscience, both of which involve capacities to exercise control over their choices, highlighting agency as a fundamental aspect of being human. In other words, humans have capabilities or capacities which ought to be protected.

Human persons cannot be treated as morally dignified beings when their capacities for agency are not respected. The willingness to exist as a symbiotic agent is an expression of agency of a person bearing rights. When thinking of a postoperative person with a BCI, we may need to revise or expand our legal ontology in ways that recognize the moral dignity of the new postoperative person. The case of Patient R teaches us that these technologies can be a critical component of one's agential existence that deserves dignified respect and protection. Accordingly, there are reasons to believe AI-personalised algorithm should not be seen as purely a neutral, technical enabling device which can be used for a variety of medical applications to achieve specific good.

An imposed removal of a BCI may have profound existential side effects. In our case above, it was more than a device being explanted

from Patient R brain. Rather, the company was responsible for the creation of a new person. The device was the property of the company, not of the patient, despite the fact she appropriated the *de novo* agential capacities—resulting in an existential dependency with the BCI. In a way, the company owned the new person; as soon as the device was explanted, that person was terminated.

Drawing upon these reflections, we argue that the capacity to exercise one's de novo agency, or to autonomously choose what happens to them (i.e. not consenting to explantation) may be considered as a basic right for agency grounded in a bodily integrity right that ought always to be respected and protected. If these rights pertaining to de novo agenitial capacities exist, then a user who consented to be implanted should (if not in all then in most cases) have their rights to refuse explantation protected, unless competence for self-determination is ruled out. If these rights regarding the inherent agential capacities truly exist, the act of removing these capabilities which formed the core foundation of Patient R's agency, may be perceived as a violation of her rights to some extent. Without these capabilities, she lost substantial degrees of her agency, suggesting a denial of her de novo self, as such infringing her possible neurorights to be that agent. Neurorights of this nature would imply that when a patient consents to be implanted with a manufactured device in an experimental setting, this should not grant the manufacturing company with the authority to unilaterally determine the possibility of explantation, particularly based solely on resource availability. The acts of consenting for implantation and explantation are not isomorphic and interchangeable notions [38,39].

5. Conclusion

Pairing AI with neurotechnology suggests the prospect of using brain stimulation for targeting a variety of symptoms, by keeping or not a user in the decisional loop. Although recent, there is an emerging academic literature engaging with the ethics of medical devices trial exit, including BCI 20, [40–46]. Aside from questions linked with technological empowerment, non-obsolescence and privacy [47,48], forced trial ending introduces fundamental questions about users' rights, particularly when devices prove to be highly beneficial to the recipient, including developing a new agential capacities [49–51]. While there are crucial studies looking into whether implanting neural device may cause personality changes, this current study provides evidence that explanting BCI may lead to long term adverse psychological and emotional effects [52].

Patient R experienced an immediate life transformation from living with the chronic symptoms of epilepsy, characterised by the uncertainty of not knowing if and when the next seizure would come, to successfully managing and preventing it with the assistance of an implantable BCI device. Our report seems to provide empirical evidence that being implanted with a BCI that monitors epilepsy can generate subjective feelings of symbiosis on the part of the patient with the "connecting" device. In the case of Patient R, this also resulted in the claim of having achieved new and beneficial agential capacities, experienced as symbiotic and being of-the-loop. The story of Patient R has a parallel in the famous science fiction film Blade Runner, where a fully autonomous agent resisted, refused, and avoided being terminated despite manufacturer order. Patient R's case is a robust example of how companies may act against the rights of implanted patients with new agential capacities. This paper hopes to encourage further investigations into the idea of neuro-specific human rights.

Credit author statement

Gilbert, F: Conceptualization, contributed to conception and design, acquisition of data, or analysis and interpretation of data, drafted the manuscript, and approved final version. Ienca, M: contributed to interpretation of data; revising draft critically for important intellectual content and approved final version. Cook M: contributed to analysis and

interpretation of data; revising draft critically for important intellectual content and approved final version.

Declaration of competing interest

Authors declare not conflict of interest.

Acknowledgements

FG research was supported by the EthicsLab. Funding from the Gwen Nettlefold Memorial Fellowship and the Goddard Sapin-Jaloustre Scholarship are gratefully acknowledged. MI has been supported by the ERA-NET NEURON project HYBRIDMIND (Swiss National Science Foundation 32NE30 199436).

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi. org/10.1016/j.brs.2023.04.016.

References

- [1] Cook M, O'Brien TJ, Berkovic SF, Murphy M, Morokoff A, Fabinyi G, et al. Prediction of seizure likelihood with a long-term, implanted seizure advisory system in patients with drug-resistant epilepsy: a first-in-man study. Lancet Neurol 2013;12(6):563–71.
- [2] Gilbert F, Viaña JNM, Ineichen C. Deflating the "DBS causes personality changes" bubble. Neuroethics 2021;14(Suppl 1):1–17. https://doi.org/10.1007/s12152-018-9373-8.
- [3] Bluhm Robyn, Cabrera Laura Y. "It's not just counting that counts: a reply to Gilbert, Viaña, and Ineichen. Neuroethics 2021;14(1):23–6. https://doi.org/10.1007/s12152-018-9391-6
- [4] Pugh Jonathan. "Clarifying the normative significance of 'personality changes' following deep brain stimulation. Sci Eng Ethics 2020;26(3):1655–80. https://doi. org/10.1007/s11948-020-00207-3.
- [5] Mosley PE, Robinson K, Coyne T, Silburn P, Breakspear M, Carter A. 'Woe betides anybody who tries to turn me down.' A qualitative analysis of neuropsychiatric symptoms following subthalamic deep brain stimulation for Parkinson's disease. Neuroethics: 2019.
- [6] Voon, et al. Deep brain stimulation: neuropsychological and neuropsychiatric issues. Mov Disord 2006;21(Suppl 14):S305–27. https://doi.org/10.1002/ mds 20963 2006 Jun
- [7] Gilbert F, Goddard E, Viaña JMN, Carter A, Horne M. "I miss being me": phenomenological effects of deep brain stimulation. Am J Bioethics Neurosci 2017; 8(2):96–109. https://doi.org/10.1080/21507740.2017.1320319.
- [8] Kellmeyer P, Cochrane T, Müller O, Mitchell C, Ball T, Fins JJ, et al. The effect of closed-loop medical devices on the autonomy and accountability of persons and systems. Camb Q Healthc Ethics 2016;25(4):623–33.
- [9] Ienca M, Fins JJ, Jox RJ, Jotterand F, Vöneky S, Andorno R, Ball T, Castelluccia C, Lozano RC, Chneiweiss H, Ferretti A, Friedrich O, Greely H, Hurst S, Merkel G, Molnar-Gabor F, Scheibner J, Vayena E, Yuste R, Kellmeyer P. A Global governance framework for brain data. Neuroethics 2022;15:20. https://doi.org/10.1007/ s12152-022-09498-8.
- [10] Gilbert F, O'Brien T, Cook M. The effects of closed-loop brain implants on autonomy and deliberation: what are the risks of being kept in the loop? Camb Q Healthc Ethics 2018;27(2):316–25 (Neuroethics Now).
- [11] Ienca M, Andorno R. A new category of human rights: neurorights. Research in Progress [Online]. Available Online at: from: http://blogs.biomedcentral.com/b mcblog/2017/04/26/new-category-humanrights-neurorights/. [Accessed 26 September 2022].
- [12] Ienca M, Andorno R. Towards new human rights in the age of neuroscience and neurotechnology. Life Sci Soc Policy 2017;13:5. https://doi.org/10.1186/s40504-017-0050-1. 2017.
- [13] Ienca M. On neurorights. Front Hum Neurosci 2021;15:701258. https://doi.org/ 10.3389/fnhum.2021.701258.
- [14] Sommaggio P, Mazzocca M, Gerola A, Ferro F. Cognitive liberty. A first step towards a human neuro-rights declaration. BioLaw Journal - Rivista di BioDiritto 2017;3:27–45. https://doi.org/10.15168/2284-4503-255.
- [15] McCay A. Neurorights: the Chilean constitutional change. AI & Society. Published on line 02 March 2022.https://doi.org/10.1007/s00146-022-0196-0.
- [16] Akmazoglu TB, Chandler JA. Mapping the emerging legal landscape for neuroprostheses: human interests and legal resources. In: Hevia M, editor. Regulating neuroscience: translational legal challenges. Elsevier; 2021.
- [17] Bublitz JC. Novel neurorights: from nonsense to substance. Neuroethics 2022;15:7. https://doi.org/10.1007/s12152-022-09481-3.
- [18] Fins JJ. The unintended consequences of Chile's neurorights constitutional reform: moving beyond negative rights to capabilities. Neuroethics 2022;15:26.

- [19] DiLorenzo DJ, Leyde KW, Kaplan D. Neural state monitoring in the treatment of epilepsy: seizure prediction-conceptualization to first-in-man study. Brain Sci 2019;9(7):1
- [20] Gilbert F. A threat to autonomy? The intrusion of predictive brain devices. AJoB Neurosci 2015;6(4):4–11. https://doi.org/10.1080/21507740.2015.1076087.
- [21] Gilbert F, Brown T, Dasgupta I, Martens H, Klein E, Goering S. An instrument to capture the phenomenology of implantable brain device use. Neuroethics 2019. https://doi.org/10.1007/s12152-019-09422-7.
- [22] Gilbert F, Cook M, O'Brien T, et al. Embodiment and estrangement: results from a first-in-human "intelligent BCI" trial. Sci Eng Ethics 2019;25:83–96.
- [23] Swan M. "The quantified self: fundamental disruption in big data science and biological discovery. Big Data 2013;1(2):85–99.
- [24] Bublitz JC. Might artificial intelligence become part of the person, and what are the key ethical and legal implications? AI & Soc; 2022. https://doi.org/10.1007/ s00146-022-01584-y
- [25] Hansson SO. The ethics of explantation. BMC Med Ethics 2021;22(121). https://doi.org/10.1186/s12910-021-00690-8.
- [26] Meyers D. Self, society and personal choice. New York, NY: Columbia University Press: 1989.
- [27] Miletic, T., Gilbert F. Does AI Brain Implant Compromise Agency? Examining Potential Harms of Brain-Computer Interfaces on Self-Determination. In Artificial Intelligence and Information: A Multidisciplinary Perspective. Eds S.S. Gouveia & J.F. Teixeira. 2020. Vernon Press.
- [28] Fulanis T, Gilbert F, editors. Is enhancement with brain-computer interfaces ethical? Evidence in favour of symbiotic augmentation. Editors Jotterand & Ienca. The Routledge hanbook of the ethics of human enhancement; 2023.
- [29] Clarke R. Cyborg rights. IEEE Technol Soc 2011;30(3):49-57.
- [30] Yuste R, Goering S, Bi G, Carmena JM, Carter A, Fins JJ, et al. Four ethical priorities for neurotechnologies and AI. Nat News 2017;551:159–63. https://doi. org/10.1038/551159a.
- [31] Van Inwagen P. Materialism and the psychological-continuity account of personal identity. Phil Perspect 1997;11:305–19. https://doi.org/10.1111/0029-4624.31. s11 14
- [32] Lavazza A. Freedom of thought and mental integrity: the moral requirements for any neural prosthesis. Front Neurosci 2018;12:82. https://doi.org/10.3389/ fnins 2018 00082
- [33] Gewirth. Human rights: essays on justification and applications. Chicago: University of Chicago Press; 1982.
- [34] Ivison D. Rights. Acumen Publishing; 2007. https://doi.org/10.1017/ UPO9781844653867.
- [35] Nussbaum M. Creating capabilities: the human development approach. Cambridge: The Belknap Press of Harvard University Press; 2011.
- [36] Sen A. Commodities and capabililties. New York: Oxford University Press; 1999.
- [37] UN universal declaration of human rights. UDHR; 1948.

- [38] Rabins P, et al. Scientific and ethical issues related to deep brain stimulation for disorders of mood, behavior, and thought. Arch Gen Psychiatr 2009;66(9):931–7.
- [39] Gilbert F. Self-estrangement & deep brain stimulation: ethical issues related to forced explantation. Neuroethics 2015;8:107–14. https://doi.org/10.1007/ s12152-014-9224-1.
- [40] Lazaro-Munoz G, Yoshor D, Beauchamp MS, Goodman WK, McGuire AL. Continued access to investigational brain implants. Nat Rev Neurosci 2018;19(6):317–8. https://doi.org/10.1038/s41583-018-0004-5.
- [41] Sankary LR, Zelinsky M, Machado A, Rush T, White A, Ford PJ. Exit from brain device research: A modified grounded theory study of researcher obliga-tions and participant experiences. AJOB Neurosci 2022;13(4):215–26. https://doi.org/ 10.1080/21507740.2021.1938293.
- [42] Harris A, Gilbert F. Restoring vision using optogenetics without being blind to the risks. Graefe's Arch Clin Exp Ophthalmol 2022;260(1):41–5. https://doi.org/ 10.1007/s00417-021-05477-6.
- [43] Sierra-Mercado D, Zuk P, Beauchamp MS, Sheth SA, Yoshor D, Goodman WK, et al. Device removal following brain implant research. Neuron 2019;103(5):P759–61. https://doi.org/10.1016/j.neuron.2019.08.024.
- [44] Gilbert F, Tubig P, Harris A. Not-so-straightforward decisions to keep or explant a device: when does neural device removal become patient coercion? AJOB Neurosci. DOI: 10.1080/21507740.2022.2126544.
- [45] Bangalore S, Messerli F. Toward a more responsible news media. Am J Med 2013; 126(5):370–2.
- [46] Lawton J, Blackburn M, Rankin D, Werner C, Farrington C, Hovorka R, Hallowell N. Broadening the debate about post-trial access to medical interventions: a qualitative study of participant experiences at the end of a trial investigating a medical device to support type 1 diabetes self-management. AJOB Empirical Bioethics 2019;10(2):100–12. https://doi.org/10.1080/ 23294515.2019.1592264.
- [47] Shook JR, Giordano J. A principled and cosmopolitan neuroethics: considerations for international relevance. Philos Ethics Humanit Med 2014;9:1. https://doi.org/ 10.1186/1747-5341-9-1.
- [48] Derks SFA. Breaching the final sanctum of the mind. Master Thesis. Tilburg University: 2021.
- [49] Clark A, Chalmers D. The extended mind. Analysis 1998;58(1):7–19.
- [50] Bublitz C, Chandler J, Ienca M. Human-machine symbiosis and the hybrid mind: implications for ethics, law and human rights. In: Ienca M, Pollicino O, Liguori L, Andorno R, Stefanini E, editors. The Cambridge handbook of information technology, life sciences and human rights. Cambridge law handbooks. New York: Cambridge University Press; 2022. p. 286–303.
- [51] Glannon W. Neural prosthetics. Neuroscientific and philosophical aspects of changing the brain. Oxford Press University; 2021.
- [52] Tubig P, Gilbert F. The trauma of losing your own identity again": the ethics of explantation of brain-computer interfaces. In: Veljko Dubljević and allen Coin; 2023. Policy, Identity, and Neurotechnology, [Chapter 3].