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Brain-Computer Interfaces and Personhood: Interdisciplinary Deliberations on Neural Technology

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Abstract

Scientists, engineers, and healthcare professionals are currently developing a variety of new devices under the category of brain-computer interfaces (BCIs). Current and future applications are both medical/assistive (e.g., for communication) and non-medical (e.g., for gaming). This array of possibilities comes with ethical challenges for all stakeholders. As a result, BCIs have been an object of both hope and concern in various media.

We argue that these conflicting sentiments can be productively understood in terms of personhood, specifically the impact of BCIs on what it means to be a person and to be recognized as such by others. To understand the dynamics of personhood in the context of BCI use and investigate whether ethical guidance is required, a meeting entitled "BCIs and Personhood: A Deliberative Workshop" was held in May 2018. In this article, we describe how BCIs raise important questions about personhood and propose recommendations for BCI development and governance.

1. Background: BCIs and Their Impact on Personhood

Brain-computer interfaces (BCIs) were first proposed in the early 1970's[1] as a tool for using brain signals to control external devices, such as prostheses and spelling software. More recently, Wolpaw et al.[2] formally defined a BCI as a "communication and control channel that does not depend on the brain's normal output pathways of peripheral nerves and muscles." When used to purposively control external devices, these systems are typically referred to as *active* BCIs[3,4]. The striking potential of these devices — one could control hardware directly with purposive thought — attracted early funding from the Defense Advanced Research Projects Agency in the United States. Since then, the diversity and amount of investment in neural devices has broadened significantly, now including contributions from large information technology corporations like Facebook and Microsoft. Private sector investment has been estimated at 100 million USD per year and is expected to grow[5]. Meanwhile, photos, videos, and representations of BCIs are promoted in press releases and spread via social media[6].

As a technology of the brain, BCIs inspire awe and a sense of possibility while giving rise to far-reaching ethical, legal, and social challenges. BCI researchers in biomedical contexts often develop and promote BCIs in terms of promised benefits to society – as new "assistive" devices, as a means to "restore" mobility or communication to the user[7], and sometimes as novel neuroscientific tools[8]. As illustrated by the UN Convention on Rights for Persons with Disabilities (CRPD), this justification for technological development is not at all unique to BCIs; signatory states are in principle obligated to study, develop, and make available new technologies that enable mobility and communication. At the same time, researchers concerned with ethics and governance of technology present neural devices as a source of ambivalence and possible harm rather than a human right. They worry, for instance, that BCIs may negatively affect the user's sense of self, complicate attributions of moral and legal responsibility, exacerbate inequality, and reshape how society understands health and disability[9]. Thus, even as BCIs are implemented to solve problems associated with medical conditions, (e.g. paralysis from stroke, traumatic spinal injury, locked-in syndrome, or autism), other personal and social problems may be created with their use.

These two seemingly contradictory perspectives on BCIs can be understood explicitly in terms of personhood, referring jointly to the features of *being a person* and *being recognized as a person*. This working hypothesis was the motivation for a deliberative workshop held in May 2018, which brought together potential BCI users, patient advocates, clinicians, and BCI developers, as well as researchers from ethics, law, the social sciences and humanities.

Building on these discussions, we present three salient cases showing how BCIs might affect personhood: 1) by altering the user's interpersonal and communicative life, 2) by their connection to legal capacity or political (dis-)enfranchisement, and 3) by way of language associated with disability and societal ability expectations. In considering each case, we suggest that what it means to be a person does not follow a stable and universal definition (e.g. a rational, autonomous, communicative, embodied human) but forms rather a contested concept. This concept haspast and future meanings with clear ethical implications given its use to describe abilities associated with a person and the social recognition attached to being a person (see Box 1). In response, we propose recommendations on how to design and develop BCIs so that they have a positive, beneficial impact, based on a deeper understanding of the effects of BCIs on personhood for individuals and for society at large.

Box 1: The concept of personhood

The concept of personhood has a long history in Western thinking, especially in philosophy and theology. It should not be confused with personal identity (i.e. what distinguishes persons from each other), personality, or self. Personhood often refers to two related sets of criteria: abilities and social recognition. On the one hand, personhood can be used to refer to the abilities or features that one must possess to be a person, within a particular socio-political and cultural context. At the same time, personhood can also refer to the social recognition that someone is "a person," with the rights and responsibilities that follow[40]. Though not entirely distinct, these two categories taken together constitute a culturally important dynamic: humans are *socially recognized as persons* to the extent that they *embody a set of characteristics and abilities expected of a person*, such as consciousness, self-awareness, self-determination, rationality, autonomy, communication, morality, participation, movement, and other traditionally expected characteristics (a certain physiology). These can all be weighted differently according to one's culture or preferred theoretical framework.

2. Experiencing Personhood in Communication and Interpersonal Life

The most obvious impact of BCIs on personhood concerns the capacities they are meant to provide the user: communication or movement. In clinical contexts, many individuals who consider using BCIs are affected by conditions such as amyotrophic lateral sclerosis (ALS) and other forms of paralysis that drastically reduce motor and/or communicative abilities. Beyond the loss of motor function, the loss of the ability to communicate can negatively impact the nature and quality of interactions and relationships with others. Family members and caregivers often have an "intuitive dependence on language as a sign of emotional

connection"[10]. The fracturing of these relationships can have fundamental impacts on the individual and has been directly linked in the context of dementia to experiences of lost personhood[11]. It is this loss that many neural technology are designed to counteract; existing BCI devices have been used to give users new forms of control over their movement and have provided them with access to social activities, such as communication, painting, self-expression, competition (e.g. Cybathlon), as well as participation in research studies. In one recent study of BCI home use, seven of 14 patients chose to keep their systems after the study ended; because six of these seven users could at the time neither speak nor write, communication with others was by far the most common usage[12].

The promise of some BCIs can thus be understood as a promise to sustain the relational underpinnings of an individual's personhood, enabling some users to better express and present themselves as persons who have thoughts, desires, and goals. However, this desirable outcome should not be taken for granted. Research studies do not in themselves assure long-term support for the technology's users[13], and some users have reported feeling like scientific objects, while others have been labeled as "BCI illiterate" due to their inability to use the technology[14]. More fundamentally, the benefits of BCIs may also be predicated upon the existing social network into which they are introduced. For individuals who have developed sophisticated and intimate forms of interpersonal communication with others, BCIs may not provide any additional benefit to what has already been established, and may have minimal effect on how the individual is recognized as a person. An individual with advanced ALS who was offered the opportunity to use a BCI to communicate with his wife refused because "after 58 years of marriage, she knows what I'm going to say anyway"[15].

In a diametrically opposite example, an individual with locked-in syndrome who had succeeded in communicating by means of a BCI decided to stop using it because he was transferred to a nursing home where he had no familial communication partners[16]. Here too, the BCI had minimal effect on this participant's personhood, as it was integrated into a network where there were no relationships to maintain or augment. BCIs have the maximal potential to affect an individual's experience of personhood if they are integrated into a larger network where the prospective user has willing communication partners who are struggling to maintain a relationship in spite of the user's limited means of interaction.

3. Legal Capacity and Political (Dis-)Enfranchisement

In light of documented problematic experiences with communication devices in clinical and political situations, it is safe to say that BCIs are also likely to impact personhood in legal and political contexts[17]. Being a person in the legal sense means being the subject of

specific rights and duties. According to the Universal Declaration of Human Rights[18] (article 6) and to the International Covenant on Civil and Political Rights[19] (article 16), every human being has the right to be recognized as a person. This guarantee is not dependent on any personal characteristics; disabled and non-disabled people alike are persons, rightholders and dutybearers, regardless of whether they use a BCI. However, the exercise of rights ("legal capacity") may vary according to one's abilities and legal expectations. The degree to which mental capacities are necessary to exercise rights is hotly debated at the moment in light of the 2008 UN Convention on the Rights of Persons with Disabilites (CRPD)[20], which guarantees disabled persons equal recognition (article 12.2). Wherever capacities are prerequisites for exercising the rights associated with personhood, technologies like BCIs may affect an individual's ability to do so.

Recent legal cases in Spain illustrate this possibility with an analogous technology. In 2000 and 2006, two Spanish locked-in persons who had been deprived of their civil rights, specifically the right to vote, reclaimed them in court[21]. The right to vote was given back to the patient who had recovered mobility of a finger and became able to communicate via computer. However, the same right was refused to the other person, who could communicate only by blinking, and was therefore dependent on a human interlocuter. By turning direct dependency on another human being into an obstacle, "assistive" technology is understood as enabling only if it brings about the realization of individualistic autonomy, a feature that was in this context implicitly considered constitutive of legal personhood. In contrast with a human-to-human interaction, which was seen as susceptible to manipulation, the system that afforded interaction between a human being and a machine was viewed as allowing the expression of a subject's genuine and autonomous will.

The Spanish cases show how technology and legal/civic personhood are often linked by way of obligations on the part of the state or the citizen. Under the CRPD[20], states are obliged to take "appropriate measures", which could include providing assistive technologies, to enable persons to exercise rights on their own (article 12.3), maintain "maximum independence", and fully participate in social life (article 26). States may therefore have to commit to some far-ranging obligations to promote the design and use of "assistive" BCIs. On the other hand, if BCIs are taken up by a diversity of publics for both casual and serious uses (as are smartphones), the obligations felt by society or imposed through human rights laws to provide BCIs to specific groups could be blunted. Moreover, as BCIs become widely used, citizens might be expected to use them, and voting stations and courtrooms may not be adapted for individuals who lack certain abilities but decline the use of BCIs. Both

possibilities illustrate a more general phenomenon related to the incorporation of novel technologies into societal structures and expectations. Societies tend to adjust to the widespread uptake of technologies in ways that make it difficult for individuals to opt out of using them[22], thus creating or altering pre-conditions for the realization of personhood.

4. Exclusionary Narratives and the Medical Framing of BCIs

Finally, but perhaps most importantly, the impact of BCIs on personhood is mediated by language. Even outside of legal texts, words generally influence perception, thought, and action[23] and "create emotional experiences and perceptions"[24]. Especially when applied as labels or narratives for people, words can affect individuals' self-image, and enable or disable them through self and public stigma. The Deaf community's rejection of cochlear implants as a "cure for deafness" illustrates this possibility and has already been highlighted as a cautionary tale about the unintended negative effects of neural technology[25,26]. We expect that BCI development and use will involve similar challenges, in part because it often relies on one of two dominant narratives about BCI users. While there are exceptions to these two narratives, the description of BCI users — as either medicalized or able-bodied — can shape what societies expect from them and has several important effects on personhood.

In the first narrative, many publications and media reporting about BCI research employ a medical deficiency vocabulary with regard to the target group. Words such as "patient" link negative medical sentiments to the targeted end-users, who are described as disabled people or people with disabilities. For similar reasons, BCIs are depicted as an "assistive technology," while other, more widely-used technologies that assist (like bicycles) are not[27]. Although some prospective users may identify with a deficiency narrative, eager to restore their bodies to a previous state, many disabled people do not understand themselves as needing medical treatment[28]. This is most evident in the criticism of narrowly medical narratives by international disability rights movements since the 1970s[29]. Even for individuals who desire the core functionality of a BCI device, medical narratives and the accompanying pressure to use the technology threatens their status as complete persons with *or without* the device. Medical ideals of normality and health may, for instance, provoke self-stigma and public stigma[30]. At the societal level, viewing disabled people as medically-deficient can also limit their participation in many aspects of society, such as policy decision-making[31], despite their right to do so as persons.

Not all BCIs are medical, however. In the other dominant BCI narrative, the end-user of recreational BCI applications, such as gaming, is frequently defined as simply the "user" or

"consumer." Disabled people are not mentioned within this narrative, and the technology is not typically labeled as "assistive" even though it explicitly supports the abilities of the user. While these consumer-oriented descriptions do not question disabled people's status as persons, neither do they solve their insufficient participation in developing and using non-invasive BCIs[32]. In sum, both narratives suggest that we need to carefully attend to the language ("assistive", "restoring", or "BCI illiterate") used in BCI development and promotion, and more importantly, include the voices of intended beneficiaries. While potential users may not describe these tensions in terms of "personhood", their language reveals their unique relationship to cultural expectations about what it means to be a person and be recognized as such.

5. Keeping Personhood in Mind: Guidance for Development and Governance of BCI Technology

Our examination of these three domains — social and communicative, legal-political, and linguistic — suggests that personhood is not merely a narrow Western philosophical concept. The many benefits and harms associated with BCIs are inextricably tied to implicit assumptions about what it means to be a person and this kind of concern is widely shared. In the past and today, being denied the status of person (e.g. because of a lack of an expected ability or characteristic) is a common form of injustice, which has been explored in critical theory of race and, more recently, in ability studies[33]. Conversely, realizing that status is not only individually fulfilling, but also grants the individual moral and political standing in society. BCIs may enable both of these possibilities, while occupying an ambivalent position with respect to our current understanding of the human person. Cultural norms and values regarding personhood guide and inspire BCI development (section 2), but BCI development and use could also challenge or even modify these norms.

While workshop attendees proposed a variety of definitions of personhood, we agreed that understanding the impact of BCI technology means inquiring about the notions of personhood that drive BCI research. Who promotes these understandings of personhood (whether those who use or desire BCIs are included) and on what basis (e.g. scientific evidence, power relations, wishes of users, etc.)? Answering these questions requires attending to the history of personhood – not only to how its meanings and enactments have changed over time, but also to its uncertain future[34,35]. In the case of neural technologies, the duty to answer these questions is shared across multiple sectors of society; technology developers, academic researchers, and the public must reflect on implicitly-held standards for personhood, the values that they represent, and the ways they will be reinforced or

changed by novel biomedical devices and narratives. Though BCIs are certainly not the only technology that present these challenges, the current stage of research and development in the field provides a unique opportunity to address them before they impact society at large.

To this end, we propose preliminary recommendations for the design and governance of BCI technology. Collectively, they set an overarching goal for BCI developers and policy-makers: BCIs should support the flourishing of individuals and the pursuit of their valued goals and preferences, rather than perpetuate oppressive or exclusionary understandings of personhood. Drawing on the workshop deliberations, we call for attention and guidance in each of the three domains mentioned above: user experience, legal and political (dis)enfranchisement, and BCI narratives. Table 1 shows recommendations that were proposed by at least a subset of workshop participants as promising directions for future research, as well as ethics and policy deliberation.

First, we present recommendations that highlight core abilities that are associated with the user's positive experience of personhood and that should be supported by any new technology. This goal partially overlaps with the basic need for effective, reliable BCI devices that are easy for the user to control and have no undesirable side effects; this will be a challenge given that current BCIs can be frustratingly slow despite extensive user training[36]. Some users may desire a simple mechanism (e.g. a command or on/off switch) by which they can "veto"[37] a BCI action before it is completed or another means by which they can foreground their agency. More fundamentally, BCI design should aim to enable lasting social participation, self-expression, movement, and other abilities in ways that meet the user's needs, self-understanding, and social relationships. This may entail making the device visually concealed and operationally unnoticeable to the user in some cases and highlighting it as simply a wearable tool for others. Translating these concerns into concrete design guidance will require empirical investigation into user experiences of personhood (or lack thereof). Globally, a person's positive experience will entail substantive stakeholder involvement throughout technology design and application.

Table 1 – Workshop Recommendations in Three Domains

Positive User Experiences	Legal and Political Recognition	Inclusive Narratives
Design BCIs that support human abilities and experiences that are constitutive of being a person	Protect ability to exercise legal and political capacities, equal to that of non-BCI users	Avoid narrowly medical framing of neural technologies

Give users a role in design through participation and self-representation	Preserve legal ownership of the self, including in some way technologies and resulting data	Cultivate and explore a broader range of roles for BCIs
Clearly separate person-guided and automatic elements of BCI, with control or veto mechanisms	Establish rights to modify device algorithms and functionality or to refrain from BCI use	Ground BCI narratives in the actual self-understandings of potential users
Design BCIs that are reliable, easy to use, minimally invasive, and suited to the individual	Adapt legal system to address vulnerability associated with BCI use	Evaluate the rhetoric used at every stage of BCI research, application, and marketing

Guidance is also needed regarding the prevention of disenfranchisement and harm in political and legal contexts. The Spanish voting cases suggest that BCIs could be crucial in exercising the rights associated with personhood and ought to be designed in such a way that the user is not disadvantaged relative to non-BCI users. This is a complex task, implicating both technical engineering questions and, inevitably, local or national socio-legal norms. Threats and changes to a user's BCI device may need to be re-conceptualized legally as interventions on the person, and regulated or prohibited when appropriate. We also may want to give the user rights to ownership of and control over the device and its data. That may conflict with the present-day norm of manufacturer-forced updates, opaque machine-learning algorithms, restrictive intellectual property laws, and end-user license agreements. To the extent that the affordances of BCI use are a core part of a users' subjective and intersubjective experience of personhood, the underlying technical systems and data traces will require legal protections beyond that given to private property; the BCI device and its digital footprint may even need to be regarded as part of the body.

Perhaps most crucially, the connection between BCIs and personhood demands more inclusive modes of technology creation and governance. The current lack of diversity in science and engineering is a known problem, but presents particular challenges in designing neural technology that does not rely on narrowly medical or stigmatizing narratives. For BCI developers, we recommend a "resonant design" approach to conceptualizing and developing technology. In contrast to designing for a particular disability or medical condition — which may diminish personhood through exclusionary language (section 4) — resonant design is intended to address the needs of some people with a specific disability and also other people without that disability, who find themselves in particular circumstances[38]. Finding a resonant need – in this case, the ability to communicate without speech or movement – across groups of individuals emphasizes the applicability of BCIs in context, diminishing the

stigma and exclusion that can be associated with the technology. Some examples of groups with resonant needs for a BCI may include parents attempting to soothe babies to sleep while also requiring something to be brought to them, hunters who are waiting for their prey and need to communicate with their families, or firefighters calling for support in a high-decibel blaze. Narratives about potential users could still be used to motivate and justify technology development, but only when grounded in respectful engagement with potential beneficiaries. Beyond the context of development, we recognize that the use of exclusionary or stigmatizing BCI language is a general problem in public discourse[39], across university press releases, funding agency websites, and even posts on social media.

7. Conclusion

In sum, we have suggested that BCIs, like many other technologies, are an active site for the continued cultural negotiation over the definition and implications of being a person, i.e., personhood. Because BCIs represent both a hope of enabling the recognition of persons and a risk of perpetuating exclusionary expectations, BCI design and development must be pursued with these dual effects in mind. Engineers, neuroscientists, science writers, technology firms, and policy-makers working on BCIs all have a duty to identify the ways in which their activities impact the meaning and enactment of personhood. Guidance is particularly crucial in enabling user experiences of their status as persons, in protecting legal and political personhood, and in avoiding exclusionary and stigmatizing effects of technology. We have proposed recommendations to this effect, but further inclusive and transdisciplinary deliberation is needed on the specific contexts of BCI development and use.

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