

Brain-Computer Interfaces, Inclusive Innovation, and the Promise of Restoration: A Mixed-Methods Study with Rehabilitation Professionals

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Abstract

Over the last two decades, researchers have promised “neuroprosthetics” for use in physical rehabilitation and to treat patients with paralysis. Fulfilling this promise is not merely a technical challenge but is accompanied by consequential practical, ethical, and social implications that warrant sociological investigation and careful deliberation. In response, this paper explores how rehabilitation professionals evaluate the development and application of BCIs. It thereby also asks how the BCIs come to be seen as desirable or not, and implicitly, what types of persons, rights, and responsibilities are assumed in this discourse. To this end, we conducted a web-based survey (N = 135) and follow-up interviews (N = 15) with Canadian professionals in physical therapy, occupational therapy, and speech-language pathology. We find that rehabilitation professionals, like other publics, express hope and enthusiasm regarding the use of BCIs for assistive purposes. They envision BCI devices as powerful means to reintegrate patients and disabled people into social life but also express practical and ethical reservations about the technology, positioning themselves as uniquely qualified to inform responsible BCI design and implementation. These results further illustrate the nascent “co-production” of neural technologies and social order. More immediately, they also pose a serious challenge for implementing frameworks of responsible innovation; merely prescribing more inclusive technology development may not counteract technocratic processes and widely held ableist views about the need to augment certain bodies using technology.

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Keywords

brain-computer interfaces; rehabilitation; co-production; disability; innovation

Introduction

Transcendence, Rehabilitation, and Neural Practices

“Brain-computer interface” (BCI) refers to a wide range of devices that establish an artificial connection between a brain region and its surroundings, including other parts of the brain, other parts of the body, or an external computer. Legal scholar and theorist Sheila Jasanoff (2016) notes the cultural significance of this technology, drawing our attention to the abstract images of BCIs, circuitry, and the brain that circulate online and in other media, and to their associations with “posthumanity” and transcendence of the human condition. However, Jasanoff stresses that these evocative futures visualized through BCIs leave implicit the deliberative mechanisms and sociological dynamics that make such technology possible in the first place. Critical scholarship in science and technology studies (STS), ethics, and adjacent fields is thus faced with a dual challenge; it must document the transcendent possibilities attributed to BCIs and other applied neuroscience, as well as their implicit dependence on pre-existing deliberative processes, social practices, and shared beliefs. This means asking “how does neural technology come to be seen as desirable or undesirable and what types of persons, from patients to engineers, rights, and responsibilities are co-constituted in the process?” Scholars in STS and critical neuroscience have already begun to map such processes through empirical study, noting that the neuroscience and its ethics creates “regimes of normativity” (Pickersgill 2013) that span neuroscientific research on morality, research governance, and new subfields in applied ethics. Vidal (2009), working across history, philosophy, and anthropology, explains how cultures of “brainhood”—the widely shared idea that persons are, in essence, brains—have served as the foundation and not the result of contemporary neuroscience. Implicit ontologies of the “cerebral subject” are thus widespread, observed even in the subjectivities of experimental BCI users (Kögel and Wolbring 2020; Vidal and Ortega 2017).

Against this background, more recent forms of neural technology are “co-produced” (Jasanoff 2004) alongside several expert and lay publics, each contributing in their own way to the normative salience of BCI devices in society. Most prominent, at least symbolically, are the targeted users: persons with limited motor or communication abilities. Researchers actively promote BCIs and other “neuroprosthetics” as responding to the urgent needs of people with neurological disorders, including locked-in syndrome, paraplegia, and depression (Leuthardt et al. 2004; Shih, Krusienski, and Wolpaw 2012). Previous scholarship on cochlear implants highlights the serious “biopolitical” or “biosocial” dynamics of being targeted for such technology development, including but not limited to the biomedicalization of deafness and the rejection of Deaf culture and related ways of being (Mauldin 2014; Blume 2009). A study of social media narratives has observed individuals with various targeted conditions demonstrating neural technologies’ medical or assistive function with positive and sometimes unrealistic commentary provided by ostensibly able-bodied BCI developers. One video misleadingly depicts a person with tetraplegia using an experimental BCI to pick up a bottle of coffee with a robotic arm; this recorded feat, an ability that is not remotely feasible outside of a laboratory, is paired with scientists described as “euphoric” about “how far science has come” and about the benefits for all paralyzed people (Purcell-Davis 2013).

When asked directly, some users of BCIs for clinical or assistive purposes do seem to be positive about the devices and would even accept some risks when using them ([Klein et al. 2016](#); [Kögel, Jox, and Friedrich 2020](#)), which contrasts with the attitudes of relatively concerned and able-bodied publics ([Sample et al. 2019](#); [Funk, Kennedy, and Podrebarac Sciupac 2016](#); [Jebari and Hansson 2013](#)). A positive attitude towards the technology, however, does not imply that potential end-users are full participants in the processes of BCI development. One recent interview study reported that BCI researchers indeed orient their work around ideas of disabled users (among others), but sometimes rely on second-hand information about what such users may want from the technology; researchers even express uncertainty about how to use such information ([Sullivan et al. 2018](#)). This lack of direct engagement with potential end-users' needs can generate misunderstandings or reinforce stigmatizing and ableist attitudes. There is evidence of such a user-expert gap occurring in the BCI development literature ([Schick Tanz, Amelung, and Rieger 2015](#)). One discourse analysis of expert BCI publications shows that most users are described as “patients,” even though many potential users would reject such labels as perpetuating a deficiency narrative about them ([Wolbring and Diep 2016](#)). Another recent study finds that the language used to describe idealized BCI users creates problematic expectations for people with disabilities ([Kögel and Wolbring 2020](#)).

To the extent that BCI development is routinely initiated without close end-user engagement, it is then the research institutions and the BCI developers themselves who decide the aims of their work and its impact. Most notably, the interdisciplinary field of “neural engineering” or “neuroengineering” has functioned to bring together a range of experts to build novel devices for assistive or clinical purposes. One handbook of neural engineering promotes the field as an “emerging discipline” and a “collaboration among biologists, mathematicians, computer scientists, and engineers” ([Akay 2007, ix](#)). As with the creation of dedicated neural engineering textbooks, the field has been at least partially institutionalized, with its own journals (e.g., *Journal of Neural Engineering*, *Brain-Computer Interfaces*), academic centers, medical device companies, and annual conferences. Even researchers in the humanities, social sciences, and law have participated, specializing in “neuroethics” since an inaugural conference in 2002 ([Marcus 2002](#)). Unlike its technical counterpart in neural engineering, the justification and scope of neuroethics has been subject to substantial disagreement ([Racine and Sample 2018](#); [Racine and Aspler 2017](#)), including doubts about whether neuroethics methods are sufficiently rigorous to influence technical practices. One critic has even asserted that the imagination of neuroethicists has been defined and even captured by the technologies themselves ([De Vries 2005](#); [2007](#)). Indeed, a central justification of this subfield is the assumption that BCIs are objects that pose special ethical and societal challenges ([Wolpe 2004](#)).

At least one other public is consequential in this domain. In Canada and many other countries, long-term treatment of paralysis and several other conditions targeted by BCIs is not usually handled by neural engineers or any of the aforementioned groups but rather by clinical practitioners in rehabilitation-related fields. Although investigated by only a few studies, the collective attitudes of rehabilitation professionals towards emerging assistive technologies are consequential for the social dynamics of BCI use ([Boehlen and Sample 2020](#); [Djebrouni et al. 2019](#)). Professionals in this area typically promote interventions designed to maximize participation in meaningful activities and subjective quality of life; this can often take the form of restoring disabled persons to “normality” and independent function, or, when this is not possible, to restore the person to a state that is as close to “normality” and independence as possible ([Gibson and Teachman 2012](#); [Hammell 2010](#)). Disability studies scholars and activists, as well as voices within rehabilitation, have

critiqued the normative practices in this profession, noting how rehabilitation perpetuates the medical model of disability or, relatedly, the view that disability should be eradicated ([Magasi 2008](#); [Roush and Sharby 2011](#); [Stiker 1999](#)). And yet, the ideology of bodily normality is still central to frameworks widely used by rehabilitation professions, such as the International Classification of Functioning, Disability and Health ([Hammell 2015](#)).

Like their counterparts in science, engineering, and biomedical research, a few rehabilitation professionals have already enthusiastically taken up the promises of neural engineering, even developing BCIs themselves and co-authoring joint aspirational statements in specialist journals (e.g., [Ereifej et al. 2019](#)). Technology has also become a focal point in some academic discussions of disability and normality in rehabilitation practice. Writing for their fellow clinical practitioners, Buetow, Martínez-Martín, and McCormack ([2019](#)), for example, propose reorienting rehabilitation around function rather than normality. For them and some other professionals (as illustrated by the popularity of Assistive Technology Makers' Fairs), technology is key to fulfilling a vision for a more inclusive, "ultrabilitative" field of practice. This recent discussion in the literature builds on a longer history of unresolved ambiguities in the normative goals of rehabilitation practices regarding disability and dependence. Common assumptions regarding the nature of the therapy professions (e.g., helpful, needs-based, client-centered) and the nature of their goals (e.g., striving for normality, increasing physical function and independence to enhance quality of life) underpin the culture through which this public engages with BCIs ([Hammell 2010](#)). Given these complexities, it is yet to be seen how the community of rehabilitation experts might shape the development and use of BCIs.

The Current Study

As with other publics, a closer examination of rehabilitation professionals, their attitudes, and their self-understandings vis-à-vis neural technology helps to document the many and sometimes conflicting ways in which technology and social order are created together. The present paper pursues this "co-productionist" line of inquiry further by adapting a previous quantitative survey of lay public concerns regarding neural technology and deploying it for rehabilitation professionals. Then, follow-up interviews are used to identify some of the beliefs and implicit reasoning behind the quantitative findings. We thus connect measurement of the self-reported attitudes and concerns of rehabilitation professionals regarding BCIs to a broader set of qualitative evaluations regarding the development and use of BCIs. This revealed among our participants an openness to the assistive and clinical promise of the technology, expectations that disabled individuals will accept BCIs to access social goods, and the ideal of rehabilitation professionals as gatekeepers in responsible innovation.

Methods

Participants

Web-Based Survey We conducted a web-based survey targeting rehabilitation professionals in Canada who

specialize in physiotherapy, occupational therapy, speech-language pathology, and art therapy.¹The survey was promoted through national and regional professional associations across Canada (e.g., Canadian Association of Occupational Therapists), using both email newsletters and websites. Prospective respondents were invited to provide their expert input on the “ethics of brain-computer interfaces.” As a modest incentive to join the study, respondents were offered the chance to participate in a follow-up interview for which they would receive 50 CAD.

A total of 249 survey responses were received, 135 of which from respondents who consented to participate, responded affirmatively to a seriousness check (i.e., were not taking the survey simply to read the questions) ([Berinsky, Margolis, and Sances 2014](#); [Shamon and Berning 2020](#)), and met our inclusion criteria. Respondents were excluded if they met any of the following: worked outside of Canada, worked outside of the four target professional fields, reported neither clinical experience nor experience with motor or communicative difficulties, or left the survey before reaching the last page. [Table 1](#) describes the sample characteristics.

Follow-Up Interviews Among respondents who indicated interest in completing a qualitative follow-up interview, 15 respondents were selected, with consideration of diversity across language, region, gender, and reported BCI knowledge. Phone interviews were conducted (in both English and French), each lasting between 30 and 60 minutes.

Table 1. Descriptive statistics for the respondents’ characteristics (N = 134–135)

Variables		Descriptive Statistics	
Categorical Variables	Percent		Observations
Province			
• New Brunswick	9.6		13
• Manitoba	10.4		14
• Quebec	72.6		98
• Other ²	7.4		10
Language			
• English	29.6		40
• French	70.4		95
Gender			
• Male	16.3		22

¹ Although recruitment materials were distributed through art therapy associations, ultimately none of the survey respondents identified themselves as art therapists.

² Other provinces were Alberta, British Columbia, Nova Scotia, Ontario, Prince Edward Island, Saskatchewan, and Yukon.

• Female	82.2		111
• Other	0.7		1
Professional field			
• Occupational therapy	57.8		78
• Physiotherapy	28.1		38
• Speech-language pathology	7.4		10
• Multiple	6.7		9
Setting of clinical work			
• Clinical (public)	41.5		56
• Hospital	14.1		19
• Private practice	20.7		28
• Multiple	11.1		15
• Other ³	12.6		17
Continuous Variables	Mean (M)	Standard Deviation (SD)	Observations
Age ⁴	41.8	11.3	135
Clinical experience (<i>in years</i>)	16.9	11.2	134
Self-reported knowledge about BCIs	2.5	2.1	135
Recommending BCIs for patients/clients	3.0	2.8	135
Inclusion of rehabilitation professionals in ethics decisions regarding BCI development and use	7.5	1.7	135

Procedure and Instruments

Web-Based Survey To enable more direct comparisons of our findings with quantitative studies of other publics, the web-based survey was adapted from a previously published survey, which measured lay responses towards a range of ethical “concerns” documented in the BCI literature (see [Sample et al. 2019](#) for additional details on survey rationale, scale design, and background on methods). We piloted the survey with rehabilitation professionals (N = 5) using post-response interviews. By doing so, we evaluated the comprehensibility of the questions and instructions. Based on the feedback, we added a qualitative question about the role(s) of rehabilitation professionals in developing and implementing BCIs, changed the

³ Other settings, for example, include professional health organizations or communities.

⁴ Age was assessed in groups of three years to uphold anonymity. To compute the mean, we took each middle category.

seriousness check, made minor changes to the survey format and wording, and added an acknowledgement of participation.

The survey starts with a briefing, providing respondents with examples of BCI use taken from neural engineering research literature ([Sample et al. 2022](#)). The intent was to create a basic shared understanding of this technology. This was paired with two pictures taken from media coverage of BCI use: one wearable device and one implanted ([figure 1](#)). The briefing was then followed by a mix of quantitative and qualitative questions regarding respondents' attitudes towards BCIs, in the following order.



[Figure 1](#): Image Left: Using a wearable BCI (Image credit, Patrick Bennet). Image right: Using an implantable BCI (Image credit, UPMC). Images and Caption provided in Web-Based Survey (Source for both images used together: US media coverage of BCI research, 2019).

- Self-reported knowledge about BCIs: BCI knowledge was assessed on a scale ranging from “nonexistent (I’ve never heard of it)” (0) to “very high” (9) ([Sample et al. 2019](#)).
- Recommending BCIs for patients/clients: whether participants would recommend a BCI to their clients/patients was assessed using a scale ranging from “not at all likely” (0) to “very likely” (9). In addition, respondents have been asked to explain their answer in an open text field.
- Inclusion of rehabilitation professionals: we asked respondents about the degree to which rehabilitation professionals should be included in ethics decisions regarding BCI development and implementation by using a scale ranging from “not at all included” (0) to “very much included” (9). An open question further asked about what roles and/or potential contributions the respondents envision for rehabilitation professionals.
- Worries and enthusiasm: we assessed respondents' worries about the possibility of applying BCI technology to six areas of life ([figure 3](#) and [Sample et al. 2022](#)) on a scale from “not worried” (coded as 0) to “extremely worried” (9) as well as the respective enthusiasm from “not enthusiastic” (0) to “extremely enthusiastic” (9) to do so ([Sample et al. 2019](#)). Open-ended questions further asked for comment on other applications respondents might be worried or enthusiastic about.
- Concerns: after asking respondents openly about their concerns about BCIs, if any, and about the ethics or social effects of BCI technology, respondents' concerns were measured with 26 items on a

scale from “not concerning” (0) to “extremely concerning” (9). These items contained brief definitions of each concern and two short examples ([figure 2](#)).⁵



[Figure 2](#). Concerns towards BCIs (N = 134 to 135). Scale for worry items ranged from “not concerning” (0) to “extremely concerning” (9). M = mean, SD = standard deviation (indicated by error bars).

⁵ The source material can be accessed for the item wording ([ibid.](#)).

We also assessed professional demographics such as education (rehabilitation-related, specifically), field and area of practice, years of experience, and experience with individuals with limited motor/communication abilities ([table 1](#)).

Follow-Up Interviews were semi-structured, and all questions were open-ended. Interview questions were designed to gain an in-depth understanding of the participants' evaluation of BCIs and/or other assistive technologies, to engage them in broader reflection on the topics described (more narrowly) as "worries/enthusiasm" and "concern" in the web-based survey, and to inquire into their visions for stakeholder involvement in technology development and implementation. Interviewees were also asked about the role of the "average Canadian" in technology development. After conducting four interviews, several sub-questions were added to further prompt and increase the quality of responses, though no changes were made to the primary interview questions or the overarching interview structure.

Data Analysis

Quantitative Analysis We provide descriptive information about the distribution of the answers of the web-based survey (e.g., mean values, share of responses), as well as Pearson correlation coefficients between selected items to examine bi-variate relationships between them.

Qualitative Analysis Interview recordings, once professionally transcribed, were analyzed in MAXQDA software. We were guided by Hsiu-Fang Hsieh and Sarah Shannon's ([2005](#)) "directed content analysis" approach (a type of qualitative content analysis), and the purpose of which was to "validate or extend conceptually." Per this approach, we deductively developed an initial coding guide from the literature on engineering ethics, health/rehabilitation ethics, and responsible innovation (including STS). This yielded the following types of codes: (1) ethical and social concerns related to BCIs, (2) uses of BCIs, and (3) inclusive development and implementation of BCIs and other assistive technologies.

Following the directed content analysis approach, we then coded all qualitative survey questions and transcribed interviews, modifying pre-existing codes and creating new codes when data did not fit into the categories derived from the literature. It should be noted that though including pre-existing categories into qualitative interview questions is suggested by Hsieh and Shannon ([ibid.](#)), all of our interview questions to be analyzed were open-ended, and so did not point participants towards certain responses corresponding to these categories.

Two of the authors (MS and WB) individually coded each of the surveys (qualitative questions) (N = 135) and interviews (N = 15). They met on a regular basis to reconcile differences in coding and coding structure. Two other authors (ER and SS) regularly reviewed the coding structure and suggested adjustments as needed (and most were minor).

Research Ethics Review

Ethics approval for this study was received from the research ethics board of the Institut de recherches cliniques de Montréal (ethics approval number: 2018-904).

Results

Imagined Uses of BCIs—Enabling Better Living through Able-Bodiedness

How do rehabilitation professionals envision the use of neural technology? When prompted with a list of possible applications, rehabilitation professionals were especially worried about the use of BCIs in the contexts of marketing and commerce, as well as military, police, and security use (figure 3). In contrast, they reported much less worry regarding applications in the areas of healthcare and assistive technology, as well as education and learning. For all of these domains except for marketing and commerce, enthusiasm is almost the inverse of worries (figure 4). The relatively large standard deviations for these items indicate that the reported attitudes of the respondents varied widely.

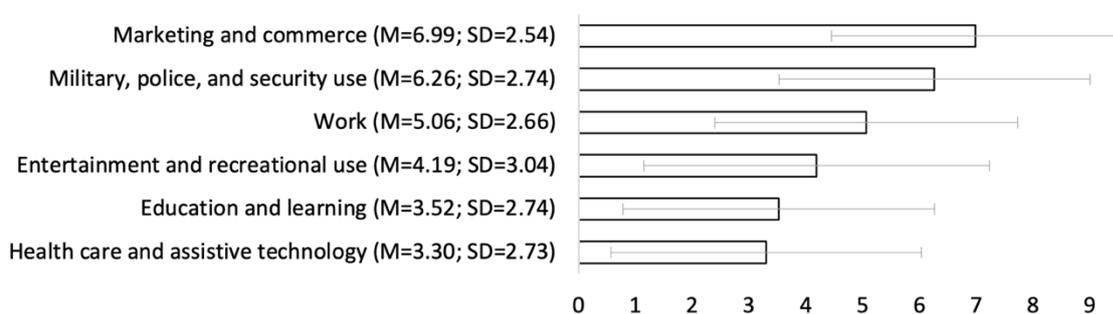


Figure 3. Worries about the domains of application of BCIs (N = 132 to 135).

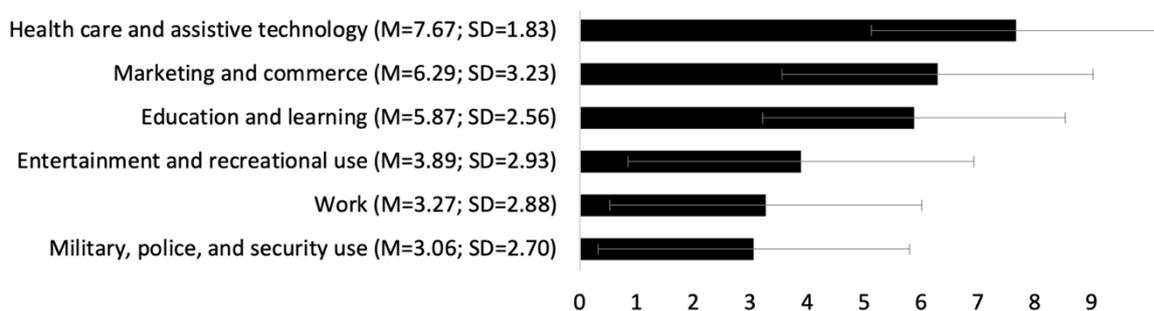


Figure 4. Enthusiasm about the domains of application of BCIs (N = 132 to 135). The response option for worry ranged from “not worried” (0) to “extremely worried” (9), respectively and from “not enthusiastic” [0] to “extremely enthusiastic” (9). M = mean, SD = standard deviation (indicated by error bars).

Across both open-ended survey responses and follow-up interviews, participants envisioned many different applications for BCIs in their practice. However, assistive or clinical applications were by far the most discussed, with some participants even suggesting that the use of BCIs be strictly limited to clinical or compensatory purposes. Motor and communication assistive functions were especially salient (table 2). Participants discussed restoring motor function to users with paralysis due to, for example, injury, locked-in syndrome, amyotrophic lateral sclerosis, stroke, or quadra- and tetraplegia. Improving mobility, including for those with amputations or using an electric wheelchair, was mentioned as a related use. Many participants thought that using a BCI for these purposes would have a significant positive impact on a user’s life by enabling greater independence, social participation, and community involvement *through able-*

bodiedness. This expectation of positive impact also accompanied imagined communication applications for similar user groups.

Other respondents envisioned uses that are much less common in the BCI research literature. These included applications for sensory and sensory-motor functioning, mental or cognitive health, daily functioning and home healthcare, and support of healthcare staff. In the latter case, the idea to remedy a shortage of support staff with technology was sometimes proposed without discussion of why there might be limited rehabilitation resources in their province in the first place. For all of the above applications, BCI use was linked by participants to a range of values typically associated with the goals of rehabilitation practice, like client autonomy/independence, community and social integration, and social interaction, as well as empowerment and the reduction of inequality.

Table 2. Themes/codes and exemplary quotes of primary BCI applications

Theme/Code	Quote	English Translation
Restoring Motor Function	“C’est sûr aussi que si ça accélère beaucoup leurs déplacements, ça épargne leurs bras, ça leur permet de marcher, faire des sports, ça l’augmenterait beaucoup leur implication dans la communauté. En emploi, leurs perspectives seraient beaucoup moins limitées. Ça fait que tout ce qui est leur participation dans leurs habitudes de vie, leur participation sociale serait vraiment augmentée.”	“Certainly, if it speeds up their movements a lot, it spares their arms, it allows them to walk, play sports, it would greatly increase their involvement in the community. In employment, their prospects would be much less limited. It means that everything related to participation in their life habits, their social participation would be truly improved.”
Restoring Communication	“Yeah, [I would consider recommending a BCI], especially with, like, communication and all, if that’s a really big barrier, being able to communicate with others. I’ve seen how even just like a communication board can help with that. If they can be completely hooked up to a computer and actually be able to talk through it.”	
Other Uses	“[. . .] avec les maladies d’Alzheimer, de la clientèle qui demeure à domicile [. . .], les clientèles ont moins de capacité d’apprentissage à proprement dit, mais ils ont besoin d’aide technique compensatoire pour se souvenir de leur médication. [. . .] Parce qu’il y a des gens qui veulent rester chez eux, mais qui n’ont pas nécessairement le personnel de soutien pour être là tout le temps pour répondre à leurs besoins ou pour appeler s’ils ont besoin d’aide facilement.”	“[. . .] with Alzheimer’s disease, clients who live at home [. . .], that clientele has less learning capacity as such, but they need compensatory technical assistance to remember their medication. [. . .] Because there are people who want to stay at home, but don’t necessarily have the support staff to be there all the time to meet their needs or to easily call if they need help.”

Willingness to Recommend a BCI and Underlying Factors

Given their willingness to imagine BCIs as assistive or healthcare devices, we also wanted to understand respondents’ attitude towards the use of BCIs in their own professional practice and any associated concerns.

Based on closed-ended survey responses, almost every tenth (8.8%) respondent expressed an (extremely) high willingness to recommend BCI technology to their clients or patients. On average, this willingness was, however, low ([table 1](#)). Willingness was positively associated, albeit weakly, with the respondents' self-attributed BCI knowledge, i.e., respondents with more knowledge had a higher willingness to recommend and vice versa ($r = 0.18, p = 0.029$). The self-attributed BCI knowledge was, however, also low ([table 1](#)), with only a small fraction 3.7% of the respondents indicating a (very) high level of knowledge.

Besides a general lack of knowledge, respondents' concrete concerns about the technology may also play a role in the hesitations to recommend BCIs. When presented a range of possible ethical "concerns" documented in the BCI literature ([Sample et al. 2019](#)), participants reported moderately high levels of concern, but again, with relatively large standard deviations, indicating that the rehabilitation professionals had diverging views ([figure 4](#)). Still, of most concern on average was the possibility that BCIs may provide unprecedented access to things that are normally private (e.g., personal characteristics, biometrics, usage data, private thoughts, etc.) and record them without consent. Of second highest concern was the possibility of serious malfunction or failure that may place users in difficult situations (e.g., increased vulnerability to digital threats, inability to perform work tasks, loss of autonomy, etc.). Of least concern was the possibility that BCI users be seen as "cyborgs" ("a mix of machine and person"), and the promotion of a medical model of disability, in which disability is believed to stem from individual limitations that BCIs are intended to "fix," regardless of whether the user considers themselves to be ill or in need of "fixing."

When we asked participants directly to describe what factors affect their willingness to recommend the technology, they most commonly referenced two things ([table 3](#)): a lack of information and the appropriateness of BCI technology for their particular clientele.

Table 3. Themes/codes and exemplary quotes of primary factors for recommendation

Theme/Code	Quote	English Translation
Lack of interviewee Information	"C'est sûr que plus qu'on est au courant de ce qui existe, on est plus à risque de recommander. . . . Si on ne sait pas ce qui existe, on ne peut pas non plus deviner. On a beau faire des recherches, des fois il faut que l'information soit accessible."	"Of course, the more you know about what exists, the more likely you are to recommend. . . . If you don't know what exists, you can't guess either. No matter how much research you do, sometimes the information has to be accessible."
Relevance to clientele	"Ma clientèle présente des maladies mentales sévères et persistantes. Ils manquent d'habiletés sociales et ont des difficultés d'ordre affectif. Je ne sais pas comment les ICO [interface cerveau ordinateur] pourraient les aider."	"My clientele presents with severe and persistent mental illnesses. They lack social skills and have emotional difficulties. I don't know how a BCI could help them."

Regarding the former, participants felt either that insufficient information was available or that they personally had not learned enough about BCIs, including about their availability, costs and potential issues, and benefits. This frank hesitation mirrors the quantitative findings. In fact, many had not even heard of BCIs prior to the survey. Participants gave several reasons for their lack of knowledge or the lack of available information: the stage of BCI development, the sparsity of current BCI clinical use, the lack of relevant

research and evidence, and simply lack of awareness on their own part. A few participants mentioned that they would be more likely to recommend a BCI if more scientific and clinical information was available or if the existence of BCIs was more widely recognized. However, for many, hesitation about BCIs was more fundamental; participants expressed that BCI use would simply not be applicable in their area of practice or to their clientele, who may not have sufficiently serious motor or communication limitations to warrant the technology. Others shared concerns that their clientele lacked important capacities, such that BCI could pose dangers such as increased complications during falls.

In the open-ended interactions, a wide range of ethical concerns were mentioned in passing, mirroring the diversity of “ethical concerns” presented in the survey. These included (but were not limited to) stigma, device reliability, safety, degree of invasiveness of the device, and lack of regulation and policy guidance. However, three themes were discussed with greater frequency and conceptual depth: digital threats, accessibility (of the technology), and informed consent (table 4).

Table 4. Themes/codes and exemplary quotes of primary ethical concerns

Theme/Code	Quote	English Translation
Digital Threats	“I mean, people with severe disabilities are, you know, they’re used to having to give up a lot of privacy. . .” But still . . . I think people with disabilities are pretty vulnerable to that kind of loss of privacy and even manipulation and so on. And so, I think that would be a concern. ‘Data is being collected supposedly about what’s going on in my brain, you know. What’s happening with that? Where’s it going?’”	
Accessibility	“Je travaille dans le système public et j’ai peu d’espoir qu’une interface cerveau-ordinateur soit payée par le gouvernement ou à prix abordable pour mes clients. Je me dis qu’un jour peut-être, quelqu’un fera un calcul permettant aux gestionnaires de trouver l’ensemble de l’utilisation d’une ICO [interface cerveau-ordinateur] moins cher.”	“I work in the public system and have little hope of an BCI being paid for by the government or affordable for my clients. I’m thinking that maybe someday, someone will do the math to allow managers to find the whole use of a BCI [to be] less expensive.”
Informed Consent	“Most of [the] time our clients can’t communicate their thoughts when they reach a severe stage of the disease, they can only respond to yes/no questions . . . The evaluation of their cognitive abilities could become a challenge in terms of ensuring they understand the process and procedures . . . How could we make sure we have their full consent before a surgery that can potentially lead to major risks [such] as death?”	

Regarding accessibility, participants believed that BCIs simply may not be available to individuals or health institutions because (1) they are not currently routinely used or made available at the workplaces of

respondents, (2) some individuals and institutions are located in small or remote communities with less access to healthcare and technology, (3) BCIs are expensive and may not be (sufficiently) covered by insurance, and (4) respondents were unaware of where to obtain support for the use of BCIs. This belief had a clearly ethico-political valence; participants asserted that BCIs should be available to all who need them, regardless of socioeconomic status, health status, or other factors, and that if this is not the case, social inequalities may be deepened. There was also a concern that access to BCIs, if determined in a democratic fashion, may be blocked; they worried that an able-bodied majority, without stake in or understanding of assistive BCI technology, would discourage use of the technology.

When it came to the possibility of data misuse, participants were concerned that personal data accessed via a BCI may be leaked, pirated, mined, or used for commercial or marketing purposes. They were also concerned that this access could allow third parties to control thoughts, device output, or user action to harm the user. As one participant pointed out, these risks are especially important for individuals who have lived with a disability, as they have had to give up privacy and dignity in receiving care and may be vulnerable. This concern brought up questions of data ownership and the level of control over the BCI and data recording the user would have.

Relatedly, participants emphasized the necessity of informed consent. They were concerned that obtaining informed consent would be difficult due to the potentially limited cognitive, decision-making, and communication capacities of prospective users. Some thought that prospective BCI users may not fully understand the implications of BCI use, such as the possibility of digital threats and the risks of device implantation surgery. They said that user understanding may be hard to ascertain if, for example, users are paralyzed and rely on technologies that can only give “yes” or “no” responses. To ensure informed consent, participants said that those creating and distributing BCIs must be transparent about the stage of the development of BCIs and the associated benefits and risks.

Vision of Technology Development and Use—Rehabilitation Experts as User Representatives

Beyond simply exploring envisioned applications of BCI technology, we also asked participants to what extent rehabilitation professionals should be included in the responsible development of such applications. On average, they were likely to prescribe a high level of inclusion ([table 1](#))—more than half of the respondents (56.3%) indicated that rehabilitation professionals should be (very) much included. This data point, of course, is embedded in a more complex set of understandings of participants’ social world and its relation to rehabilitation practice. These are exemplified in our qualitative findings.

In open-ended survey responses and follow-up interviews, participants invoked a wide range of actors in technology development. They cited not only the necessity of experts who are already predominant in spaces of experimental assistive technology, like engineers, clinicians, and users, but also actors more distant from those spaces, such as industry professionals, consumers, lawyers, ethicists, spiritual leaders, health policy makers, patient advocates, and users’ family members. Although we did not identify a singular ideal for technological development, participants tended to discuss BCI development as something that implicates many different segments of society, even as they expressed uncertainty about how that happens exactly. Nevertheless, the three most prominent themes were discussed in sufficient detail to describe here: a need to integrate end-user perspectives, the role of rehabilitation professionals in a collaborative process of BCI development, and ambivalence towards the involvement of non-expert publics ([table 5](#)).

End-users, notably, comprised an essential part of the envisioned development process. For most participants, “end-users” referred to disabled individuals, patients, or other persons who would be directly using the BCIs; for others, “end-user” also meant health professionals or individuals supporting those who would be using the BCIs. Though many participants did not specify exactly when or how end-users should be involved in the development process, it was very important to participants that end-users be consulted or included in some way. Some mentioned that user input would be particularly helpful in early stages of development, while others thought that they should be involved throughout the entire development process. According to participants, the input of end-users could help ensure that BCIs reflect the actual needs of users, improve the relevance and practicality of BCIs, and make sure they are suitable for real-life situations. Overall, participants seemed to conclude that end-users should be included because they are most impacted by the technology. This was contrasted, for instance, with members of the general public or “the average Canadian”; participants were not always convinced that the democratic value of wide participation in technology development outweighed the possibility for ignorance or lack of interest from the general public.

Table 5. Themes/codes and exemplary quotes concerning technology development

Theme/Code	Quote	English Translation
Need for End-User Perspectives	“[T]hey [the user] can ask, you know, they can make it better because they can have comments and questions and share some ideas on their needs, and then the engineers can create some function to meet their needs.”	
Rehab Professionals as Collaborative Contributor	“Je crois que les professionnels seraient bien placés pour réfléchir aux besoins des usagers, aux conséquences possibles dans le différent milieu de soins (domicile, centre de réadaptation, soins aigus et de longues durées, etc.), à l’entraînement qui serait requis et la faisabilité de ces entraînements.”	“I believe that professionals would be well-placed to think about the needs of users, the possible consequences in the different care settings (home, rehabilitation center, acute and long-term care, etc.), the training that would be required and the feasibility of such training.”
Ambivalence towards the General Public or “Average Canadian”	“I think [Canadians] totally deserve a voice. Whether they want to use their voice is a different story. If somehow their voices could be potentially heard, I think it would be really beneficial. But then it comes down to whether they want to use their voices. It almost feels to me like voting, like in elections and stuff.”	

Equally unambiguous, participants saw themselves, as rehabilitation professionals, contributing much-needed expertise to an ideally collaborative process of creating and using BCIs responsibly. In stressing the value of collaboration, they frequently saw themselves as the only specialists who would actually screen, train, and monitor BCI use once the technology becomes more widely available. They would have a role in determining therapeutic BCI uses that align with user goals and integrating this into treatment plans and

into the daily lives and activities of users. Rehabilitation professionals would also be responsible for adapting and personalizing devices to individual users, as well as working with users throughout the entire process.

But even before BCIs become routinely used in clinical settings where rehabilitation professionals work, their perspectives are still promoted as essential. Most participants were quick to identify their unique contributions to the more experimental processes and spaces of BCI development. Many of these envisioned inputs were related to their health expertise and the knowledge of the needs of prospective BCI users by virtue of working directly with them. Rehabilitation professionals often, for instance, develop rapport with their patients/clients and may have access to privileged information about them. Participants said that, on a BCI development team, only rehabilitation professionals would bring unique insights into biological and physical health, including principles of movement, client/patient positioning, preventing pressure sores, and sensory sensitivities in different populations; processes of recovery; neural rehabilitation and how to train brain recovery; and complex health issues, including the cycle of grief and the impact on an individual of being able to use a BCI e.g., to communicate. Participants also claimed specialized knowledge of specific clientele, e.g., older adults, including common challenges and needs of certain populations—though they are aware and sensitive to the wide diversity of potential BCI users and their needs.

Engineers and information scientists, in contrast, were described as possessing important technical expertise but lacking these contextual insights. In this way, participants positioned themselves as interceding on behalf of the end-user, translating user experiences and needs for other experts. For some, but not all participants, this even extended to the domain of ethics. Echoing the survey items centered on ethics, some participants suggested that rehabilitation professionals may be able to provide feedback on ethical guidelines, provide opinions on ethical aspects of BCI use based upon their experience, and raise novel ethical issues based on observation of BCI use. The deontological codes followed by healthcare professionals, they suggested, could help them provide insight into equitable BCI development and use. However, at least two participants expressed worry that ethical validation is simply not within their scope of practice.

Discussion

By querying the attitudes and self-understandings of rehabilitation professionals with respect to BCI use and development, our study further illustrates an important dynamic in society: the co-production of an emerging technology with particular forms of social order, including the appropriate applications of technology, the implicit rights and responsibilities of disabled users, and the ideal role of professional practices in innovation. New technologies, even those that are still highly experimental and rarely used, will inevitably be shaped by longstanding values and interests of implicated publics. In the present study, our findings about professional attitudes towards BCIs are relevant to at least two scholarly literatures—STS and responsible innovation—and can be discussed accordingly.

Ethics and the Co-Production of Devices and People

As indicated by the extensive BCI ethics literature, the stakes of neural technology are widely considered to be high. Despite their stated promise as life-changing assistive technology, BCIs evoke many questions and doubts for ethics researchers ([Burwell, Sample, and Racine 2017](#)) and other publics ([Sample et al. 2019](#); [Funk, Kennedy, and Podrebarac Sciupac 2016](#); [Nijboer et al. 2013](#)) alike. This dual character of the technology can

appear in both quantitative data—high levels of concern and worry, when measured separately—and in the thematic complexity of qualitative assessments of BCIs. We find that rehabilitation professionals are no exception to these trends. Despite their professional background, they did not show higher levels of self-attributed knowledge about BCIs than the general public ([Sample et al. 2019](#)). They also reacted with ambivalence, citing concern towards a wide range of issues in BCI ethics (e.g., misuse of data), even withholding a recommendation of the technology to their clients. These findings seem to echo another recent survey of occupational therapists in training ([Djebrouni et al. 2019](#)). Yet, despite similarities between professionals and other publics, a commitment to STS constructivism discourages universalizing the abstract idea of BCIs in society but to ask how and for whom such understandings come about? We thus have to look at how and with what values the social world is being co-produced alongside technoscience and, in this case, within the specific context of our study and resulting interactions with participants.

We find that, when presented with the idea of BCIs as promoted by technology developers, rehabilitation professionals are very willing to imagine their positive use and even express enthusiasm for the sociotechnical promises implied therein—BCIs are to be used for medical and assistive purposes, with great potential for addressing disability and for improving lives. Entertaining this still-distant promise of the technology, an openness to its hypothetical desirability, implicitly creates an understanding of the human in society. Motor and communication abilities are centered, like in neural engineering, as crucial for a good life and a functional body, perpetuating a medical model of disability or judgments of individual ability deficiency ([Wolbring and Diep 2016](#)). Implications for the rights and responsibilities of disabled people quickly follow; the would-be user must modify their body and behavior to access these promised benefits, including independence and social participation. In this way, rehabilitation professionals do not seem to pose a challenge to parallel BCI discourses in the neural technology research literature, in popular media and press releases, and the broader “economy of technoscientific promises” ([Audétat 2015](#); [Joly 2010](#)). Counter-imaginaries and alternative models for the use of assistive technology do exist, of course, within disability studies (e.g., the social model of disability) and disability rights advocacy movements beyond academia ([Shakespeare 2006](#)). One could, for instance, imagine that BCIs should be recommended only after all community or environment-based interventions have been exhausted. Or, alternatively, they might be designed to be used by anyone regardless of bodily ability. We did not, however, encounter those ideas in our study.

That said, rehabilitation professionals do bring their own imagination of how BCIs might fail to fulfill their restorative promise; they emphasized the ways in which the technology might be impractical in context, be inappropriate for the user, or be unavailable. Based on experience working with clients who have motor or communication limitations, negative stories or hypothetical scenarios were ready at hand for rehabilitation professionals to explain. These took the form of both explicit ethical concerns and, less explicitly ethical, misgivings about practical utility. While likely acknowledged by other actors, these concerns were also presented by rehabilitation professionals as uniquely within the domain of their clinical practice and thus a reason for greater inclusion in processes of BCI development. In this way, rehabilitation professionals not only reinforce the significance of other emerging publics (neural engineers and BCI users) but also implicate themselves as crucial gate keepers for proper BCI design and use.

These results should be understood in the context of disciplinary training for rehabilitation professionals. In Canada, the core competencies of communicator, collaborator, and change agent are

fundamental to the occupational therapy education curriculum ([Canadian Association of Occupational Therapists 2012](#)). This training received by all practicing occupational therapists is well-aligned with our results, which highlight the dual role of the rehabilitation professional in engaging with new interventions and technologies and acting as advocate for the needs of their clients. Similarly, in the essential competencies to assess a student's readiness for entry-to-practice developed by Physiotherapy Education Accreditation Canada (PEAC) and the Canadian Physiotherapy Association (CPA), several core skills implicate physiotherapists in their role as gate keeper for proper BCI design and use. For example, physiotherapists are expected to "Employ assistive and augmentative devices to enhance communication" (Essential Competency 2.4.1), "Maintain awareness of emerging technologies, and advocate for their application to enhance physiotherapy services" (Essential Competency 5.2.1), and "Champion the health needs of clients" (Essential competency 5.1) ([National Physiotherapy Advisory Group 2017](#)); together, these competencies implicate physiotherapists as responsible for learning about and engaging with BCIs. This is perhaps not surprising but indicates a possible internal tension in the profession between promoting technology as an intrinsic good and advocating for clients' needs, which may be more complex. This tension may also be inherent in the rehabilitation sciences generally, which must constantly negotiate between idealized goals and the limits of actual practices ([Rochette et al. 2014](#)). This dynamic constitutes an important part of the socio-political world into which BCIs are being introduced.

Responsible Design of BCI Devices

Beyond advancing STS literature on emerging technology, our findings also have relevance for the responsible design of BCI devices. Scholars working within the frameworks of responsible innovation or public engagement often point to multi-stakeholder inclusion as an obvious means for improving technology ([Rowe and Frewer 2005](#); [Stilgoe, Owen, and Macnaghten 2013](#)), but the extent to which rehab professionals are willing to entertain the restorative promise of BCIs suggests that they may not serve a fully critical or evaluative role in assessing the technology. As long as professional curricula, in addition to social media discourse, rely on unquestioned assumptions about the value of technology and restoring "normal" human flourishing ([Kögel and Wolbring 2020](#)), the role of rehabilitation professionals in inclusive innovation is not straightforward. Somewhat more worrisome, as positioning themselves as key actors in understanding user preferences and needs, rehabilitation professionals might even contradict actual users in the name of inclusive or responsible innovation. Indeed, such tensions should be expected, given critiques of technology in disability studies, as well as STS theory on the political stakes of technology ([Winner 1980](#)).

There may be ways to address these negative outcomes. Several design practices have been noted for their putative ability to incorporate ethical considerations into the design of assistive technologies, including user-centered design and participatory design ([Madsen et al. 2009](#)). Both approaches strive to engage the end-user in all stages of the design process, creating a space where mutual learning, collaboration, and "designing together" can take place ([Muller 2003](#)). While this design approach has been successful in creating designs that reflect the perspectives and preferences of future users in simple technologies, complex technologies such as BCIs pose distinct challenges to this design approach. Technical decisions around signal processing techniques, machine learning strategies, etc. are imbued with ethical implications for the end-user, who may not be able to engage in the design conversation without genuine knowledge of the computational side of the system, and a clear sense of what the algorithms can and cannot

be expected to do ([Cowie 2011](#)). As a result, much neural technology development has occurred with only superficial stakeholder engagement, leaving much of ethical decision-making primarily in the hands of the technology specialists.

In keeping with the participants' aspirations, herein lies a space in future BCI design practice where the rehabilitation profession can fill an unmet need: as practitioners who develop "interactional expertise" ([Collins, Evans, and Gorman 2007](#)) that allows coordination between the technology specialists and the needs and desires of the end-user in the context of their lived experience. But taking on this role is likely not to be as simple as deploying unique, pre-existing knowledge across and between publics. As other authors have noted, such collaborations should be situated within a broad institutionalization of "governance of ability expectations" in technology development, including changes in professional training ([Djebrouni et al. 2019](#); [Wolbring and Diep 2016](#)). Otherwise, harmful assumptions about the disabled subject's rights, responsibilities, and overall place in a technological society may counteract the promised benefit of "inclusive" innovation practices.

Limitations and Directions for Future Research

As with any study, the choice of methods introduces limitations to the results and their interpretation. Specifically, these findings should be interpreted as situated within a context, Canada and especially Quebec, from which the majority of participants were recruited. Results are thus shaped by regional and national particularities in history, language, culture, and healthcare policy. This is evident, for example, in the way respondents' notion of device accessibility is not oriented solely around device cost, but also around BCI availability through Quebec's medical technology procurement procedures. For this reason, future research, perhaps comparative in approach, should examine if and how regional or national particularities affect the perspectives of the rehabilitation professionals and what they may share across contexts via the action of professional networks. Furthermore, because many participants' first in-depth exposure to the idea of BCIs and associated ethical concerns was through our survey, qualitative findings should not be read simply as pre-existing attitudes; they are at least partially moderated reactions to ideas and texts deliberately drawn from scholarly BCI research literature. For this reason, the evaluations of BCIs, assumptions about disability, and professional ideals of technological development we find entangled in this discourse are to some extent unique to our study, pending complementary ethnographic research. These specific caveats should be considered in addition to the more general limitations of using directed content analysis (see [Hsieh and Shannon 2005](#)).

Conclusion

As previous literature in STS shows, technoscience is deeply implicated in the creation of identities, professional and otherwise, and collective understandings of meaningful human life. BCIs are no exception. Rehabilitation professionals have the potential to influence the social understandings and uses of BCIs as they are responsible for treating many of the conditions targeted for BCI use (e.g., paralysis). In documenting the perspectives of rehabilitation professionals in Canada, this study found that medical and assistive applications were most favored, especially to restore motor function and communication, and that digital threats, accessibility, and informed consent were of particular concern. Many rehabilitation professionals, however, asserted that they have limited BCI knowledge or that they treat individuals for whom BCI use

would not be deemed appropriate. Our results showed that rehabilitation professionals believe that their expertise alongside end-user input are necessary throughout BCI development and implementation processes, though they are ambivalent about the role of non-expert Canadian publics in these processes.

Generated in the course of this study, the data and discourse we analyzed can be understood as a specific instance of co-production. Existing technoscientific promises are taken up and adapted according to the normative self-understandings of rehabilitation professionals, who attempt to envision a role for their practice and their clients in pursuing these promises. We suggest that the ambivalence therein, neither purely hopeful nor pessimistic, is linked to tensions inherent in professional training and culture. Overall, our observations gesture to more general features of “neural” life and subjectivity, from algorithms for translating brain activity to BCI press releases on social media, which are co-produced alongside ethically and politically significant social configurations: community participation is linked to an able body, persons with disabilities are expected to change themselves, and experts position themselves as part of the responsible creation and governance of an emerging technology.

Our findings also complicate frameworks in responsible research and innovation. In theory, rehabilitation professionals are obvious stakeholders to include, as a way of ensuring that the technology responds to the actual needs of its intended beneficiaries. However, the fact that respondents understood themselves, in addition to end-users, as central to BCI development complicates this prescription. To the extent that rehabilitation professionals are willing to entertain and even echo some of the problematic promises of neural engineering, their presence in technology development and use may demand more thorough integration of actual user perspectives and values. Given this, their reservation about recommending the technology shows an important tension with an underlying professional commitment to pursue technological solutions. “Inclusive” collaborative spaces for technology design will have to take this into account.

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Data Availability

Data that supports the article by Matthew Sample et al., can be accessed in STS Infrastructures at <https://n2t.net/ark:/81416/p4ks36>.

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