

Keeping Disability in Mind: A Case Study in Implantable Brain–Computer Interface Research

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Abstract Brain–Computer Interface (BCI) research is an interdisciplinary area of study within Neural Engineering. Recent interest in end-user perspectives has led to an intersection with user-centered design (UCD). The goal of user-centered design is to reduce the translational gap between researchers and potential end users. However, while qualitative studies have been conducted with end users of BCI technology, little is known about individual BCI researchers’ experience with and attitudes towards UCD. Given the scientific, financial, and ethical imperatives of UCD, we sought to gain a better understanding of practical and principled considerations for researchers who engage with end users. We conducted a qualitative interview case study with neural engineering researchers at a center dedicated to the creation of BCIs. Our analysis generated five themes common across interviews. The thematic analysis shows that participants identify multiple beneficiaries of their work, including other researchers, clinicians working with devices, device end users, and families and caregivers of device users. Participants value experience with device end users, and personal experience is the most meaningful type of interaction. They welcome (or even encourage) end-user input, but are skeptical of limited focus groups and case studies. They also recognize a tension between creating sophisticated devices and developing technology that will meet user needs. Finally, interviewees espouse functional, assistive goals for their technology, but describe uncertainty in what degree of function is “good enough” for individual end

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users. Based on these results, we offer preliminary recommendations for conducting future UCD studies in BCI and neural engineering.

Keywords Brain–machine interface · Brain–computer interface · Disability · Research ethics · User-centered design

Introduction

Brain computer interfaces (BCIs) are computational systems that form a communication pathway between the central nervous system and some output, be it a device or feedback to the user (Wolpaw and Wolpaw 2012; Rao 2013). Given potential improvements in communication, motor control, and autonomic function, advances in the field of neural engineering are often heralded as holding great promise for persons with sensorimotor disabilities (Hochberg and Anderson 2012). According to a recent review, “the major purpose of BCIs is to improve the quality of life for the patients who use them” (Murphy et al. 2016). Targeted patient populations are diverse, including, for instance, individuals with amyotrophic lateral sclerosis (ALS) and people who have experienced spinal cord injuries or stroke (Yuan and He 2014).

BCI research is relatively young, with systematic experiments of human–computer interfaces conducted in the 1970s (Shih et al. 2012) and the first successful human trial of wearable BCI for communication in 1999 (Birbaumer et al. 1999). BCI systems involving implantable components offer the promise of greater signal fidelity, consistent placement of recording and stimulating electrodes, and ease of use. The first implantable BCI trial began in 2004 (Hochberg et al. 2006), and BCI technologies are increasingly being implemented in clinical settings (Murphy et al. 2016). While reviews of clinical applications of BCIs note technological, neuroscientific, and pedagogical barriers to BCI implementation (Murphy et al. 2016; Yuan and He 2014; Lotte et al. 2013), the field of neural engineering has displayed increasing interest in barriers related to attitudes, perceptions, and priorities of potential end users of these technologies (Huggins et al. 2011; McCullagh et al. 2014; Kübler et al. 2015; Liberati et al. 2015; Nijboer 2015). Researchers have begun to recognize that obtaining end user views is a critical step in understanding and overcoming these barriers (Nijboer et al. 2013).

One way to incorporate end user views into BCI research is through user-centered design (UCD). UCD is a model derived from work with computerized and assistive technologies and recently applied to BCI (Huggins et al. 2011; Holz et al. 2012; Collinger et al. 2013).¹ The goal of user-centered design is to reduce what is described as a “translational gap” between researchers who develop assistive technologies and potential end users of these technologies (Kübler et al. 2014). This gap exists in the space between researchers’ ideas about which devices to prioritize

¹ The “Matching Person and Technology (MPT) model is similar to UCD, although MPT focuses on matching individual persons with disabilities to existing assistive technology (Scherer 2002; Scherer et al. 2005), whereas UCD works to incorporate persons with disabilities into the technology design process.

and potential users' actual needs and values. The motivation of UCD is twofold: to increase the speed of technology transfer such that end users have access to technologies more quickly, and to create technologies that will actually be used. This is accomplished in a number of ways: understanding user experiences and values, involving users in the design process, allowing users to evaluate technology during development, and incorporating a more holistic understanding of user experience into technology design (ISO 9241–210:210; Kübler et al. 2015). Ideally this process is iterative, allowing for multiple rounds of researcher-user collaboration.

The success of UCD intervention is measured in terms of resultant device usability, defined in terms of effectiveness (how well a BCI-controlled technology works), efficiency (the amount of effort a user must put in to use a BCI-controlled technology well), and satisfaction (how a user feels while using the technology) (Editorial 2013). Despite the growing interest in UCD in neural engineering and a number of successful applications of UCD (Kübler et al. 2014), there are barriers to successfully meeting usability goals. These barriers include high financial and time requirements for iterative, collaborative research with device users and limited study populations who can provide feedback to researchers (Kübler et al. 2015). Other studies suggest that lack of familiarity with neural engineering technologies may make potential end users uncertain about how such devices would fit into their everyday lives. A challenge for UCD is finding a way to communicate to a potential user what using a BCI would be, absent first-hand experience with a BCI device (Liberati et al. 2015).

In addition, there are indications that individual BCI researchers may not implement core aspects of UCD in their work. Consideration of the needs of the whole person (e.g., cognitive and affective in addition to sensorimotor or functional needs) is one of the fundamental standards of UCD (ISO 9241–210:210) and qualitative information about current and potential BCI end users is available (Huggins et al. 2011; Blain-Moraes et al. 2012; Zickler et al. 2013). Yet a recent study reports that BCI researchers focus on quantitative measures of the technological advancement of BCI devices (e.g., rates of user acceptance and device performance indices) rather than qualitative assessment of the cognitive–affective aspects of BCI user experiences (e.g., how users feel about the devices) (Powers et al. 2015). Understanding the values of persons with disabilities as potential end users of BCI technology and recognition of distinctions between persons with different disabilities is also often absent from the rationales articulated in published reports of BCI studies with human subjects (Specker Sullivan and Illes 2016).

Our concern is that if individual researchers do not attend to end users' perspectives and values, it is possible that, despite growing theoretical interest by the field of neural engineering in UCD, the translational gap it is designed to address will continue to exist. This gap has scientific, financial, and ethical implications. Scientifically, UCD expands the perspective from which scientific practice is undertaken, enhancing awareness of diverse approaches to problem solving and stimulating creative solutions. Financially, UCD reduces the chance that resources are wasted on the creation of unnecessary products. Ethically, UCD aligns with principled arguments that researchers ought to recognize the perspectives of persons

with disabilities and that research about persons with disabilities, without their involvement, is problematic (Charlton 1998).²

UCD is of growing interest to the field of neural engineering, yet to our knowledge, no study has assessed researchers' motivations and ability to engage in UCD. Given the scientific, financial, and ethical imperatives of UCD, it is essential to gain a better understanding of researchers' attitudes towards potential end users of their research, as researchers will be the primary drivers of UCD implementation. To investigate these attitudes, we conducted a qualitative interview case study with researchers at a neural engineering center dedicated to the creation of implantable brain–computer interfaces. The study explores whom researchers identify as “end users”, the exposure of researchers to likely beneficiaries, and researchers' sense of importance for engaging stakeholders in the research, development, and design of neural technologies.

The results show that some researchers may understand “end users” to be not just device users but also other researchers and clinicians farther along the translational pathway, in addition to families and caregivers of device users. The researchers interviewed value their interactions with end users, and personal experience is the most meaningful. They welcome (or even encourage) end user input, but are skeptical of limited focus groups and case studies. They also recognize a tension between creating sophisticated devices and developing technology that will meet user needs. Finally, interviewees espouse functional, assistive goals for their technology, but describe uncertainty in what degree of function is “good enough” for individual end users. Based on these results, we offer preliminary recommendations for conducting future UCD studies in BCI and neural engineering.

Methods

The CSNE

This study was carried out within the Center for Sensorimotor Neural Engineering (CSNE), an NSF-funded Engineering Research Center based at the University of Washington (UW), which also includes partners at San Diego State University (SDSU) and Massachusetts Institute of Technology (MIT). The CSNE is focused on the development of implantable bidirectional brain computer interfaces (BBCI) for people with sensorimotor disabilities.³ CSNE faculty and graduate students have a variety of disciplinary backgrounds. The CSNE is currently comprised of four “thrusts,” each representing an area of fundamental knowledge considered crucial for the development of neural technologies: Communication and Interface, Computational Neuroscience, Experimental Neuroscience, and Neuroethics. The authors of the present paper are all affiliated with the Neuroethics thrust.

² The distinction between practical and principled considerations captures the difference between ethical reasons that focus on instrumental outcomes (e.g., benefit or well-being) and those that focus on intrinsic duties and obligations.

³ “Bidirectional” BCIs both read from and stimulate to the central nervous system (as opposed to stimulation alone, as in the case of a deep brain stimulator).

Recruitment

Principal investigators affiliated with the CSNE at UW, SDSU, and MIT were recruited via email. Eligibility required that interviewees were listed as the PI for a project supported through the CSNE's National Science Foundation grant. Out of fifty requests, seventeen PIs responded to a recruitment email and fifteen were interviewed (two were unavailable during the interviewing period). Recruitment ended after a set window of opportunity to volunteer and a convenience sample of specialties at the CSNE was achieved. Verbal consent was obtained from all individual participants in this study, which was approved by the University of Washington Human Subjects Division.

Data Acquisition

Semi-structured phone or in-person interviews were conducted in Spring 2015 by graduate fellows in neuroethics funded by the CSNE (co-authors TB, MS, MP, and AT). This method of interviewing was chosen to allow for follow-up and clarification of interviewee responses. Interviews were conducted in one sitting. Interviews lasted roughly 1 h and were recorded, transcribed verbatim, and anonymized.

The interview guide was part of a larger study that investigated researchers' perceptions of ethical issues in their work in addition to their attitudes towards end user engagement ("[Appendix](#)"). Questions directed at end user engagement were designed to obtain information about interviewees' perspectives on the role of end users in their laboratories and in the field of neural engineering broadly. These questions ranged from the researcher's identification of and experience with potential end users of neural engineering technology to the perceived effects that end users have or would have on their research.

Data Analysis

The interviews yielded 13 h of audio recordings. No software was used for analysis. Co-authors LSS, EK, TB, MS, MP, PT, and SG conducted a thematic analysis of the transcripts and created a codebook from these initial themes. In the subsequent analysis, co-authors independently examined the transcripts for theme frequency, iteratively interpreting the data through group meetings, pair analyses, and independent assessments to develop the final set of themes (Corbin and Strauss 2015).

Results

Interviewees came from a diverse array of fields, with some PIs working across disciplines: electrical engineering ($n = 6$), mechanical engineering ($n = 2$), neurosurgery ($n = 3$), computer science ($n = 3$), rehabilitation medicine ($n = 2$),

physiology ($n = 1$), neuroscience ($n = 1$), and bioengineering ($n = 1$). Thirteen men and two women were interviewed (Table 1).

Our analysis generated five themes common across interviews (Table 2). These were: (1) identification of end users, (2) experiences interacting with persons with disabilities, (3) effects of persons with disabilities on research, (4) obligations to end users, and (5) goals of research. Here we describe the range of interviewees' responses in each thematic category. In the discussion, we describe how each theme reflects interviewees' understanding of practical and ethically principled considerations in engaging with potential device end users, and we explain the impact that these considerations have on implementation of UCD practices.

Identification of End Users

Interviewees were asked to identify the “end users” of their research. This open-ended question allowed participants to describe a range of end users. Many of the responses in this theme reflected the focus of the CSNE on neurological conditions that affect sensorimotor abilities, such as spinal cord injury, stroke-related disabilities, traumatic brain injuries, Parkinson's disease, and Amyotrophic Lateral Sclerosis (ALS).

However, not all interviewees take future device users to be their only end users. For some PIs, other scientific researchers and clinicians are the most salient group of “end users.” This was common for interviewees who work on early stages of device development, such as those working on ways to make devices smaller, or to increase device energy efficiency, or to improve device data storage and processing capacity. Interviewees working early in the translational pathway also cited companies and

Table 1 Interview participants

Specialty	Gender
1. Rehabilitation medicine	Male
2. Rehabilitation medicine	Male
3. Physiology and biophysics/neuroscience	Male
4. Neurosurgery	Male
5. Computer science and electrical engineering	Male
6. Neurosurgery	Male
7. Electrical engineering	Male
8. Electrical engineering and computer science	Male
9. Mechanical engineering	Male
10. Electrical and computer engineering	Female
11. Electrical engineering	Male
12. Mechanical engineering	Female
13. Neurosurgery	Male
14. Bioengineering	Male
15. Electrical engineering	Male

Table 2 Frequency of themes across all interviews

(1) Identification of end users

1. Consumers	3
a. People with disabilities	9
i. People with trauma-related disabilities	1
1. Spinal cord injuries (SCI)	14
a. Acute	1
b. Chronic	3
2. Limb loss	2
a. Acute	0
b. Chronic	0
3. Traumatic brain injuries (TBI)	4
a. Acute	0
b. Chronic	0
4. Paralysis (unspecified)	2
a. Acute	0
b. Chronic	0
ii. People with non-trauma-related disabilities	
1. Stroke	11
2. Essential tremor	1
3. Parkinson's	3
4. ALS	2
5. High-blood pressure	0
6. Cerebral palsy	2
7. Neural disorders	0
8. Hand motion impairment	1
9. Bladder and bowel control	0
10. Locked in syndrome	3
11. Sexual dysfunction	0
12. Post-traumatic stress disorder	1
b. General population	
i. Unspecific	1
ii. People in significant relations with persons with disabilities	
1. Families	1
2. Companies/producers	2
3. Health professionals	
a. Physicians/clinicians	5
b. Caregivers	3
4. Researchers	5
a. Neural engineers	1
i. Fellow CSNE researchers	3
b. Mechanical engineers	1
c. Biochemists	1
d. Scientists	

Table 2 continued

<i>(2) Experiences interacting with persons with disabilities</i>	
1. No exposure	3
2. Occasional exposure	
a. Family member	2
b. Patient groups	2
c. Study subjects	3
d. End user advisory groups	4
e. Not specified (general experience)	8
3. Regular exposure	
a. Family member	1
b. Patient groups	4
c. Study subjects	2
d. End user advisory groups	2
e. Not specified (general experience)	2
<i>(3) Effects of end users on research</i>	
1. Skeptical about input	2
a. Could skew expectations	
b. End user doesn't always know best	6
c. Everyone's different	8
d. Problems with polling method	4
i. Question formation	3
ii. Selection bias	6
2. Input encouraged	8
a. Observation	3
b. Surveys	4
c. Focus groups	7
d. Intermediaries/clinicians	14
e. Lab participation	6
f. End user advisory board	7
g. Research papers	3
h. Ethics group presentations	5
i. Interviews	8
3. Uses for input	
a. Determining priorities	42
b. Feedback on design	38
c. Lab motivation/inspiration	5
<i>(4) Obligations to end users</i>	
1. Honest communication	1
a. Risks described	5
b. Limitations described	9
c. Avoid false hope/promises	18
d. Accurately describing benefit	7

Table 2 continued

2. Quality of life improvements	1
a. Defined (specific improvements)	8
b. Undefined (general improvement)	14
3. Device quality	
a. Functionality	13
b. Usability	27
c. Safety	11
d. Longevity	9
4. No obligations mentioned	
5. User acceptance of device	29
6. Device accessibility/affordability	19
<i>(5) Goals of research</i>	
1. Restore	3
a. Restore to normal (alternative terms: cure/fix/pre-injury/regain use/regain access/complete reanimation)	15
b. Restore some lost function (alternative term: improve recovery)	13
2. Assist (alternative terms: improve function, improve QOL)	26
3. Augment (alternative terms: enhance, best, toy).	14
4. Inform (e.g., basic science)	11

industry affiliates as end users: “A third group of end users are actually the companies that maybe we convinced to invest to commercialized tech transfer” (15; in this section, quotes are identified by interviewee number (Table 1)).

Use of the term “end users” extended further beyond scientists and researchers to the families and care providers of people with disabilities.⁴ As one interviewee explained: “We have docs... and to some extent, the families as well, I think the families of the people with injuries could either be their—the quality of their life could be improved, that the caregiver burden is reduced, financial burdens are reduced, but also they’re going to be interacting with the individuals that have the implanted device, probably advising them on what’s a good idea, so I think they’re an important group to consider” (2). For interviewees, the meaning of “end user” is broad and can extend to a number of parties whose quality of life will be affected by changes in their own and others’ abilities.

Experiences Interacting with Persons with Disabilities

Interviewees were asked to describe the extent of their experiences interacting with persons with disabilities. These experiences took a variety of forms, including interviewees’ family members, patient groups, study subjects, and end user advisory groups (e.g., within the CSNE, which has an end user advisory board). Of the

⁴ While researchers occasionally used the term “end users” to refer to clinicians and other researchers, in the remainder of the article we use this term to indicate persons with disabilities who are potential users of the BCI devices that the CSNE aims to create.

interviewed PIs who are clinicians, their most common interaction with persons with disabilities was in the clinical setting.

Within this theme, interviewees repeatedly emphasized that in-person experiences with persons with disabilities were the most impactful: “I think a very effective way of doing this, I don’t know if it’s the best way, but it’s a way that I’ve experienced many times is to have a patient who’s using a device or has need for a device be part of a program and come in and talk about it” (1). Another interviewee described attending a roundtable with a person with spinal cord injury, saying, “I’m learning more from just those few minutes of our online participation than I could, you know, by reading any number of papers or books” (7). While these personal experiences were the most significant, interviewees suggested that they needed more in-person engagement with persons with disabilities: “I think that that’s one of the things that our lab has not done enough with, is actual conversation with end users” (13).

Apart from these in-person experiences, interviewees reported learning about disability perspectives through colleagues and research collaborators. Interviewees frequently described this process as translation: “I don’t think we can ignore basically the patient or the—you know, the specifications of the user, but it may be—translation may be in order for us to be able to do that” (10). Interviewees may rely on intermediaries to translate the concerns of persons with disabilities “in a language that we’re more accustomed to listening to” (7).

Effects of Persons with Disabilities on Research

Interviewees were asked whether they thought that incorporating the views of persons with disabilities, such as those with spinal cord injuries or other neurological conditions, could improve the overall design of neural devices or the interviewed PI’s own contribution to design. They were also asked about the best method to obtain end user views.

Interviewee responses revealed two distinct (although not always mutually exclusive) subthemes: *encouragement* of end user input and *skepticism* about the usefulness of end users’ input. Encouragement was the most common subtheme. Interviewed PIs encouraged end user input through particular means (such as surveys, focus groups, observation, lab participation, end user advisory boards, or published papers) and for particular purposes (such as to determine research priorities, to provide feedback on design, or to serve as lab motivation and inspiration).

Interviewees often commented that learning more about the priorities and goals of people with disabilities would likely change the trajectory of research. One interviewee stated, “I think understanding what the functional goals are of the users would absolutely dictate the architecture of the system at almost every level” (3). Another participant highlighted the need to obtain end user input on devices with medical functions:

I think if you’re saying that... I’m doing it for medical purposes to help people, then I think you automatically are in a situation where you have to

start taking their input into consideration because they might just say at the very beginning, I'm never going to use that device. And if 100% of everybody that has that condition is not going use that device, then it's a no go (12).

Interviewed PIs observe that devices based on medical needs must take users' perceptions of those needs into account for the device to be successful.

While the importance of device user input was readily acknowledged by interviewees, one noted that it is not often discussed in the field: "But if the person actually can't put a sensor on their hand by themselves, what good is it? In our community, you could read a thousand papers in JMEMS [Journal of Microelectromechanical Systems] and never see that issue mentioned once" (7). PIs express interest in a venue for discussing these issues.

When interviewees were skeptical of device user input, they cited problems with sampling (such as differing opinions or epistemic limitations) or secondary concerns (such as expectations being affected by the wording of the surveys themselves). For example, one interviewee was cautious about extrapolating from a small group of potential end users' preferences or experiences to all end users:

And so, it's of course vital to have end user input, but to generalize from that end user group to everyone, you have to be careful... I mean, what I take out of that is, okay, make sure that what we're doing is broad enough and flexible enough to satisfy what the end user is saying they want (13).

Other PIs suggested that end user feedback on device usability would be helpful, but that end users would not be able to give feedback on the more technical aspects of device design, reporting instead on more practical concerns such as appearance, "I don't see the people telling me where to put electrodes in the brain [...], but [it's alright] if they tell me about what's cosmetically acceptable to them" (15).

Obligations to End Users

There were no specific questions in the interview guide about participants' obligations to end users, but these obligations were a frequent theme of PIs narratives. PIs described their obligations to end users in terms of five major themes: honest communication, quality of life improvements, device quality (including functionality, usability, safety, and longevity), user acceptance of the device, and device accessibility/affordability.

The most frequently mentioned obligations were user acceptance of the device and device usability. Acceptability of the device refers to whether or not it is accepted by end users for various reasons (including cosmetic reasons), whereas usability refers to the ease of use of the device, if it were accepted. A researcher may, for example, have to be careful not to design "the [kind of] fancy prosthetic arms that no one wears because they're too heavy, or cumbersome" (8). The goal is to create something that people will use (7). By contrast, a device may be usable without being accepted by end users, i.e., if it does not fit their needs:

It's important to consider the end user perspective because otherwise we'll build it twice. It's going to help people walk again, but what if they don't

necessarily want to walk again, right? They want bladder function, they want hand function, but they don't have it. So those are things that we have to be, I think, keenly aware of (2).

While interviewed PIs recognized end user needs, their more fundamental worry may be about wasting resources by “building it twice.”

Many interviewees combined usability and user acceptance into the notion of “good design,” often in the context of the eventual sales or success of the device: “Wearable systems are light. They are not intrusive, so it's easier to sell” (2). One interviewee, however, questioned if these two goals ought to be discussed together:

What they're saying is, 'Tell us how to make this arm better,' not, 'How can we best suit the needs of the user population.' I think it's kind of two different ways of looking at it and I think if the neural engineering community wants to address the highest priority needs of the population, I think we have to understand those needs much better than we do now (4).

This suggests that technology design should be driven by the needs of persons with disabilities from the beginning of research, rather than feedback only being sought for market ready devices.

Issues of device accessibility and affordability were also important to interviewees: “I do worry a little bit about that [affordability] that it may be kind of an elite... device” (1). However, while PIs often noted the significance of affordability, many felt that they were not in a position to make devices financially accessible (4). The main area where PIs noted that they could take cost into account was in selecting less expensive components for devices or repurposing off-the-shelf devices to accomplish short term research goals. Others suggested that if affordability is prioritized, it can be considered as a constant constraint on device development. A further concern was that the presence of these devices in some countries and not others could worsen global health disparities.

PIs frequently stressed that it is important to avoid giving people false hopes about what neural technology can accomplish. They were concerned about false hope in the context of particular patient-subject relationships and also in media portrayals of their work:

The part of where you have to be really careful with any medical device is you peddle hope, right. When somebody goes into surgery, I don't know that it's going to work, what they're buying. You know, in true economic sense, they're buying the hope that this will work (13).

Interviewed PIs may feel that by “peddling hope” to end users, they generate an obligation to meet those expectations.

Other obligations mentioned were general quality of life improvements (“I know what is going to make that person quite better, often times it's a matter of my—limitations with technology which will prevent me from delivering the potential they wanted.” (6)), device functionality, and device safety. No interviewee explicitly stated that researchers have no obligations to end users.

Goals of Research

As with interviewees' discussion of obligations to end users, there were no specific questions about the goals of neural engineering research in the interview guide. Nevertheless, the goals of research were a recurring theme across interviews. Interviewees' goals for research fell into three categories. The first goal is restoration, understood as either restoring the patient to normal (alternately "cure," "fix," "completely reanimate," "regain use," and "regain access"), or restoring some lost function (alternately improving recovery of some function). Many PIs stated that they often assumed that restoring function is valuable: "I think that there simply is in my mind a preconceived idea that restoration of function and health is a good thing" (13). This could be reinforced through direct experience: "Restoring previous neurologic function is something I've never met anybody who didn't want that on some level" (13) and "In my 17 years where I spent with injured patients, what they want is what they had" (15). As highlighted by the second theme, hearing perspectives directly from potential end users has a strong influence on interviewees.

Restoration did not always map onto specific diseases or disabilities. Rather, restoration of function was occasionally described as instrumental for a broader purpose: "you can affect an entire lifetime and you can restore the person to [...] employability" (15). Some PIs described this "restoration to normal" as socially situated:

By now you know who we're—who our target end user is, right? So I think for them what we are trying to do would lead to bring them as far to what—to finally use the word "normal" within quotes, person can do. So I don't see if it's an—I don't see it as an enhancement, I think it's helping people to live life that's—are closer to what most people around them are living (6).

Interviewees more frequently described their goals as assistive, i.e., improving function or patients' quality of life. Some explicitly avoided the language of restoration and spoke in terms of improving function: "I'm just saying, 'improve function,' I'm not saying, 'restore function'" (1). Other descriptions of improvement, include "moving people along a curve" and "it's a sliding scale" (15), as well as "good enough" functionality:

So, what's good enough function? If the individual can reach out and feed themselves in an awkward-looking movement, that doesn't look normal, but still they—you know, they get the apple to their mouth, is that good enough?" (11).

Because clinical application of these devices is a relatively distant goal, PIs may be aiming for broad improvement with more detail about function to be determined in the future.

Interviewees also looked ahead to augmentative uses of neurotechnology—i.e., enhancing patients or others' functionality, giving them the best function possible, or even providing them with an entertainment device. This was described both in terms of external pressure from the fields that comprise neural engineering and as

personal preferences for such devices. Other PIs imagine that some medical and non-medical end users will strive for “more than normal” functioning.

Discussion

In this case study of a neural engineering research center, we explore one group of researchers’ perceptions of potential end users of BCI technology and the practical and principled considerations they take into account when incorporating end users’ perspectives into their research. While previous studies with BCI researchers have focused on neural engineering researchers’ perception of potential ethical issues in the field (Nijboer et al. 2013; Grubler et al. 2014), our analysis focuses on researchers’ perceptions of and attitudes towards potential end users of their devices in the context of the goals of their research. This provides one example of how researchers consider the value and use of end user input and can serve as a starting point for exploring effective methods of end user engagement in neural engineering research.

Identification: End Users are Not Just Device Users

Interviewees’ identification of potential “end users” of their work includes patient populations commonly cited as the targets of BCI research (Yuan and He 2014) as well as other researchers and clinicians. This latter perception of other researchers as end users is unsurprising for engineers and others whose role in BCI research—and within an integrated BCI center—is to create or optimize components for BCI devices and systems. Researchers working at one stage of the translational pathway, such as electrode design, can view their work as “in service” to researchers or clinicians further along the pathway, whether as collaborators or within the BCI field more generally.

Other interviewees employed the standard meaning of “user” in UCD, which refers to designing assistive devices around the needs and perspectives of the people who will use the devices, most often persons with sensorimotor disabilities. As BCIs are generally developed in clinical contexts and target medical needs, they fit within the category of assistive devices. Yet actual BCI research spans from electrical engineering to computational neuroscience to rehabilitation medicine. This raises an important question for the implementation of UCD in BCI centers and perhaps in BCI research more generally: at what stage of technology design should engagement with persons with disabilities as end users begin, and who is responsible for its initiation?

Current models of UCD presuppose that end user engagement in research occurs at the level of device control and choice architecture, providing input on issues such as positioning of devices, buttons, alarms, and knobs, methods of device testing, ease of device use, and device reliability (Holz et al. 2012; Williamson et al. 2015). However, the perspectives of persons with disabilities may be relevant even earlier in the translational pathway. For example, the daily experience of a person with a spinal cord injury may be relevant to an electrical engineer’s work on electrode

design, or could help shape a computational neuroscience model of somatosensory feedback. Even without direct application, interaction with persons with disabilities may help basic science researchers to consider new or alternative approaches to research questions. We suggest that, for interdisciplinary fields such as neural engineering that extend along the translational pathway, further consideration of when end user engagement occurs would clarify the significance of this engagement for different types of researchers in the field.

Interaction: Personal Interactions with Persons with Disabilities have the Most Impact

Other than those trained as clinicians, interviewed researchers reported having limited experience interacting with persons with disabilities who could be potential end users of their work. When they did have this experience, they consistently described these encounters as meaningful and expressed interest in having more opportunities to directly engage with end users who are persons with disabilities. This contrasts with common methods of user engagement in BCI, which rely on qualitative researchers (often social scientists or ethicists) to conduct research with stakeholders and potential end users of technology and to report on their results through published articles or by directly talking to researchers and designers (Huggins et al. 2011; Blain-Moraes et al. 2012; Collinger et al. 2013; Zickler et al. 2013; Grubler et al. 2014; Kübler et al. 2014; Liberati et al. 2015; Schicktanzt et al. 2015). While interviewees did mention these pathways of exposure to the perspectives of persons with disabilities, they had less overall impact than in-person experience.

This is not to say that structuring engagement through intermediaries has no value. PIs described the convenience of having intermediaries, such as ethicists and clinicians, apprise them of relevant end user perspectives in a language that they can understand. Nevertheless, the absence of direct experience with persons with disabilities as end users may be one reason why some researchers do not identify persons with disabilities as end users. The concern here is not simply one of identification, but also of motivation. We hypothesize that the more researchers have personal contact with persons with disabilities, the more they will be motivated to incorporate end user perspectives into their research. If this is the case, as our results suggest, then an important variable in the success of UCD is whether engagement with persons with disabilities as end users occurs directly or through intermediaries (or both).

The most effective structure for UCD may be one in which intermediaries collect end user perspectives while also creating opportunities for researchers to engage with persons with disabilities in a more personal context (Schicktanzt et al. 2015). Here again, however, there are the challenges of timing and responsibility for initiating end user engagement—which researchers would most benefit from engaging with persons with disabilities, and when? (As we discuss below, a further question is how this engagement is structured). Intermediaries need to identify a target audience for engagement with end user perspectives, and researchers need to know whether they ought to prioritize end user engagement in their work. For

example, it may be most pertinent to engage with end user perspectives when funding priorities and basic research problems are established. Engagement with end users may become even more important as the device or system approaches clinical trials. Ultimately, the question of timing and responsibility for end user engagement is an issue that needs to be decided by each research center or lab, but it is likely that personal interaction between research and individual end users will have a greater impact on research practices.

Effect of Input: PIs Encourage End User Input but are Skeptical of Generalizability

Even though the researchers we interviewed did not always describe themselves as experienced in incorporating the perspectives of end users, they value their interaction with end users and recognize the importance of end user priorities for research and preferences for design. Some researchers suggested that end users' functional goals could shape the architecture of BCI systems at every level. Yet while interviewees recognize the benefit of engagement with end users, not all are aware of the means to do so. In addition to the need to establish mechanisms for considering the timing of and responsibility for end user engagement, there are opportunities for creative thinking about methods of user engagement (such as BrainDance, a project that brings together scientists, choreographers, and persons with Parkinson's Disease),⁵ and for outreach with researchers about these methods. As suggested above, in-person interactions may be one of the more memorable methods of end user engagement. However, we also found that some researchers are skeptical about the effectiveness of these one-off encounters for shaping engineering priorities and about the generalizability of focus groups and qualitative studies. Responding to this methodological skepticism is important when implementing UCD in neural engineering.

Some interviewees expressed skepticism that end user input could be helpful, given that many technological devices that have had market success have not been foreseen or predicted. These researchers may not know what kind of end user experience they can rely on nor what types of considerations they should take into account when referring to end users' perspectives. They may be suspicious of end users' abilities to accurately predict future adoption of devices that are still in development. It is unclear whether published studies of personal conversations, end user attitudes, or clinical interactions with patients provide sufficiently reliable testimony—or even what counts as a reliable testimony in each research context. While personal experience with persons with disabilities has the most impact, some of our interviewees extrapolated from limited personal experience with persons with disabilities to make assumptions about what would be of interest to particular populations.

Skepticism about end user input reflects concerns about selection bias in end user engagement. For example, if a focus group is comprised of BCI users alone, as a group of people who have already committed to a BCI system they may convey

⁵ For example, see: <https://braindanceenglish.wordpress.com/about-us/>.

more certainty or optimism about the technology than individuals who have not chosen to use a BCI. Even if the general public is canvassed, those who respond to a research study on BCIs may already be interested in BCIs. Likewise, researchers who draw conclusions about potential BCI end users from their clinical encounters with patients risk understanding all BCI users *as* patients, excluding the perspectives of disabled persons who choose not to seek out clinical interventions.

For UCD to be successful in BCI, input from end users must come from a diverse group of participants that (ideally) represents all of the perspectives found in potential end user groups. This would not only enhance the reliability of UCD methods, it would also serve as a corrective for BCI researchers whose work primarily involves patients and puts them at risk for a selection bias in making predictions about end user priorities. A further possibility is to incorporate comparison of methods of end user engagement into neural engineering education and training. This would ensure that researchers are aware of these methods and are learning the skills needed to engage with end users, either directly or through an interdisciplinary team.

In addition to these opportunities for addressing practical considerations in the use of UCD for neural engineering research, we recognize an additional opportunity for ethical reflection on the principled reasons it is important to engage with end user perspectives through UCD and other methods, as we describe in the context of the next two themes below.

Obligations: Making Sophisticated Devices May Not Always Succeed in Making End Users' Lives Better

While this was not a question in our interview guide, many interviewed PIs recognize that targeting a group of persons with disabilities or patients as end users generates obligations to that group. They describe these obligations in terms of device usability, acceptability, and equitable distribution. This is in keeping with the UCD model, the standards of which specify that its purpose is to: “make systems usable and useful by focusing on the users, their needs and requirements, and by applying human factors/ergonomics, and usability knowledge and techniques” (ISO 9241–210).

UCD focuses on the three components of effectiveness, efficiency, and satisfaction, and interviewees frequently combined these components under the heading of usability or acceptability. Many interviewees argued that they want to make a device that people will use. As one noted, there is a difference between trying to make a given device better, and trying to best suit the needs of the user population (4). Within engineering and technology design, these are described as the “technology push” and “need pull” paradigms (Schon 1967). The former suggests that innovation is driven by science—scientific discoveries allow for the creation of new technologies, which enjoy success by offering new forms of productivity. The latter, by contrast, argues that successful technologies respond to particular needs—that is, that innovation is pulled by a gap in productivity (Chau and Tam 2000). This is in keeping with arguments in ethics and disability studies that an easy to use

device may not be accepted if it does not serve an individual's or target group's prioritization of functional needs (Scherer 2002; Silvers 2010).

This theme identifies a tension between researchers' desire to make a device that is technologically sophisticated and a device that end users will want to use. In other words, there are elements of both "technology push" and "need pull" paradigms in researchers' practices. Many researchers working in neural engineering are trained in basic or applied science, not assistive technology design. Within this training, their focus is on determining how certain neural processes work and using this understanding to drive technological development, rather than beginning from an end user reported need and building technology around that need. There are also substantial forces impinging upon neural engineering (e.g., media, marketing, and industry relationships) that reward researchers for developing sophisticated yet inaccessible technological solutions as opposed to simple yet accessible solutions.

This is an important point of discussion for neural engineering that moves beyond UCD, because the draw of creating sophisticated yet inaccessible technologies is a major opposing force to the democratization of technological development represented by UCD. This gets at the question of not just how biomedical science progresses, but *why*. That is, it is important for the field of neural engineering to specify the values underlying BCI research, and to assess whether technological sophistication must be at odds with accessible solutions.

Goals: Assisting "Good Enough" Function is a Moving Target

Participants' diverse descriptions of the goals of BCI technology (restoration to normal, restoration of function, assistance, or augmentation) also suggest that, despite being engaged in the same general project (the creation of BCIs), particular researchers with different backgrounds have different ideas about the aim of this project. As in the identification of other professionals as end users, researchers focus on technological problem solving but, given the early stage of research, must imagine completed solutions in order to work toward them. Interviewed researchers described a number of different general goals, but most seemed to strive for "good enough" function. Some shared the assumption that, at this stage, the goal is to move users along a function curve, with the understanding that a complete reversal of symptoms is most likely out of reach. Yet it is not clear how this function curve is established, what its limits are, or what the criteria are for good enough functioning. While UCD may be a valued methodology in the field, interviewees' abstract definitions of success suggest that, between the technology push/need pull paradigms described above, they have taken up the technology push more than the need pull paradigm.

In reflecting on these data, we propose that another possible source of interviewed BCI researchers' ambivalence about implementing UCD and their implicit adherence to the "technology push" paradigm may be the absence of principled ethical justification for engagement and co-design with end users from the UCD and "need pull" literature. Arguments for UCD focus on economic efficiency reasons for end user engagement: UCD will make a device more successful on the market and will ensure that technology does not waste financial or

labor resources. Further, some interviewees who argued against co-designing systems with end users focus on the impracticality of factoring stakeholder input into low-level hardware design.

Reasons to be concerned about the success or failure of UCD go beyond practical or financial implications of creating an unnecessary product. Neural engineering, conceived as a domain of assistive technology, is premised on the fact that end users have certain needs that render assistive technology necessary (Wolbring and Diep 2016). Assistive technology fields would not exist but for the perception that persons with disabilities lack sensory and motor functionality that must be improved, assisted, or restored. If these needs are imagined by researchers rather than informed by potential end users, researchers may unintentionally contribute to the objectification of persons with disabilities as persons to be “fixed.” The ethical justification of UCD is not just that engagement with end users will make devices more successful, but that assistive technology research cannot just be *about* persons with disabilities but must also *involve* them. We suggest that creating opportunities for researchers to consider the values inherent in their work, as described above, will create spaces in which researchers can reflect on why it is important to ask persons with disabilities as end users of BCI devices what “good enough” function means to them.

Limitations

This study had a number of limitations. There are approximately 50 PIs affiliated with the CSNE, yet only 15 PIs were interviewed. Nevertheless, these 15 PIs do represent the various subfields within the CSNE’s research agenda. While the interviews do not capture all of the views of PIs within the CSNE or within the field as a whole, we believe their attitudes on end users present a useful case study from which future projects on engagement with end users in the field of neural engineering can be developed. We do not suggest in this paper that our findings are generalizable to the field. In addition, interviewees may have been acquainted with interviewers. However, given that interviewers were philosophy graduate students or affiliates and not students studying directly under any of the interviewees, we believe this does not introduce a conflict.

Conclusion

In conclusion, this study found that most of the researchers we interviewed at a dedicated BCI research center value end user input in neural engineering research, acknowledge obligations to end users, and recognize end users’ potential impact on their research. However, interviewees express uncertainty about when, how, and why to engage with end user perspectives, rely on intermediaries to apprise them of these views, and maintain a general concern about selection bias and reliability of UCD methods. Further, there may be underlying uncertainty about the intrinsically ethical reasons for implementing UCD practices.

We believe that these results highlight a number of opportunities for researchers to assess the user engagement practices underway in their centers and labs. It may be beneficial for BCI researchers to consider timing and responsibility for end user engagement in addition to methods of reliable engagement. Finally, there is a further opportunity to reflect on the more principled ethical reasons for engaging with end user. These outcomes can be summarized by the following list of practical and principled considerations in UCD and end user engagement for the field of BCI:

Practical considerations:

1. Identification of end users
2. Determination of timing and responsibility for end user engagement
3. Assessment of the significance of personal interactions with end users
4. Comparison of methods for obtaining end user views

Principled considerations:

1. Specification of the values underlying BCI research (e.g., sophistication vs. accessibility)
2. Reflection on the ethical reasons to engage end user perspectives

UCD has much promise for the field of BCI, both for ensuring that devices meet the needs of persons with disabilities and for fulfilling the ethical obligations of the field. We look forward to future research on the theory and practice of end user engagement in BCI technology.

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Compliance with Ethical Standards

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of Washington Human Subjects Division and with the 1964 Helsinki declaration and its later amendments. Verbal informed consent was obtained from all individual participants included in the study.

Appendix: Interview Guide

Ethical Issues in the Lab

Have any ethical issues come up in your lab?

Do you foresee any ethical issues arising:

- in the short term or near future?
- in the long term, or likely in the more distant future?

How have you dealt with past ethical problems?

How you foresee dealing with future ethical problems?

Do you think public policy or mass media shapes your work? If so, in what way?

Prompt: (think about FDA standards or policies, or movies or newspaper articles, or even potential interviews with the press about your work; the opening kick of the World Cup last summer came from a man with an exoskeleton)

How should CSNE researchers talk about and label implantable (or prosthetic) neural devices (in scientific articles or with the public) such that we accurately convey the limitations and actual function of such devices?

Prompt: Are there metaphors or shorthand language that we can (or should) use to present the technology in relatively accessible ways? (maybe mind-as-machine? something else?)

Prompt: Given that our discussions/representation of the brain and emerging neural technology can affect wider societal/cultural norms, how careful should we be in choosing metaphors and explanations of those things? (think about mind-as-machine metaphors, etc.).

Do you have any concerns about broader social forces that might shape this research (e.g., about how the money gets allocated or where it comes from - e.g., invested corporations, about reasons for investing in these technologies)? If so, can you describe them?

End Users

Who do you consider the end users of your research?

Prompt: Is there a specific group of people with disabilities that you think of as potential beneficiaries or end users for your research?

We recently conducted a focus group with individuals with spinal cord injury and asked them about their impressions of various kinds of neural technologies (including BCI for spinal stimulation and BCI for control of a robotic device). Participants in the focus group expressed several concerns, including ones we think may have relevance across different neurological conditions, and we want to explore some of these with you.

- Are you optimistic that *the kind of work going on in neural engineering* will significantly improve the quality of life of:
 - ...someone who *currently* has a spinal cord injury.
 - ...someone who experiences a spinal cord injury in the next *5 years*.
 - ...someone who experiences a spinal cord injury in the next *15 years*.

Why or why not?

- Are you optimistic that *the CSNE's* current research testbeds will significantly improve the quality of life of someone with a spinal cord injury? Why or why not?
- If your lab's work is related to spinal cord injury, how optimistic are you that *your lab's* current research will significantly improve the quality of life of someone from that patient population? Why or why not? (If not, skip this question.)
- Do you have any experience interacting with people with disabilities who might benefit from using these devices?

If *yes*, based on your interactions, do you think the view of persons with spinal cord injuries are optimistic or pessimistic about the potential benefits of neural devices?

If *no*, do you think the views of persons with spinal cord injuries are optimistic or pessimistic about the potential benefits of neural devices?

- In your experience, do you think persons with spinal cord injuries are concerned about privacy of information collected in use of neural devices to a greater, lesser, or about the same degree as the general public is concerned about privacy in use of technology? Why do you think this?
- In what way do you think the views of potential end users are shaped by: media portrayal of neurotechnologies?
- What about cost? When, if ever, should the eventual cost of a neural device be considered?—what part of the research pathway?
- Do you think that incorporating the views of persons with spinal cord injuries (or other neurological conditions) could improve the overall design of neural devices? Why or why not?
- Do you think that incorporating the views of persons with spinal cord injuries (or other neurological conditions, if your project is directed to a different end user group) could improve *your* current contribution to the design of neural devices? Why, or why not?
- If yes—i.e. If the views of persons with spinal cord injuries (or other neurological conditions) are valuable to the design process—what is the best way to...
 - obtain these views (e.g., focus groups or people with disabilities in the lab)?
 - make use of these views?

Incorporating End User Feedback

Sometimes end users' perspectives, their values and priorities, do not match up with a research program in neural engineering. For example, consider the controversy

around cochlear implants. And sometimes the general public is concerned about issues that aren't priorities within a research program.

- Focusing on potential end users, is it feasible to adapt your research to better account for the values or needs they have expressed?
 - If so, how do you think it can be done?
 - If not, why not?
- More generally, are you free to spend time or resources on adjusting for any social or ethical implications of your research?
 - If not, what constrains you?
- Are you in full control of the direction of research in your lab? What are the constraints on the direction of the research?
- If the Center's testbeds are successfully translated into technology that improves lives, would you feel responsible for the successes, at least in part? What if they are not successfully translated?

If no one is individually responsible for the end products of neural engineering (successful or not), should engineers and scientists strive to create conditions where researchers have more individual freedom to direct their research and its translation? How?

- To what extent are your individual decisions in day-to-day research the cause of particular technologies that the Center develops? In other words, if someone asked you to explain the existence of a CSNE-created technology, would your day-to-day research decisions probably be part of that explanation?

Specific Ethical Issues

Have you considered issues related to safety? If so, which?

Prompt: What kinds of safety concerns should potential users of the technology be concerned about? How do you think these concerns should be addressed, and by whom?

Prompt: An implantable device and/or its components may have limited lifespan or be superseded by new technology (electrodes, power source, software). If an implantable device becomes outdated or replaced by better technology, who should be responsible for maintenance, repair or replacement of the "outdated" device?

Have you considered issues related to *security*? If so, which?

Prompt: How vulnerable is the technology you are working on to unauthorized access, and what measures can be taken to insure that your technology does not open up to attack?

Have you considered issues related to *privacy*? If so, which?

Prompt: Does the technology you are working on produce or collect sensitive data? If so, what measures ought we take to ensure that this data is handled appropriately?

Have you considered issues related to *responsibility* (i.e., *who is responsible if using a BBCI leads to an accident*)? If so, which?

Prompt: Do you think your technology will alter our understanding of responsibility for thoughts, moods, motivation, action, etc.?

Have you considered issues related to *authority* (i.e., *how should control be shared between the individual and the device*)? If so, which?

Prompt: Do you think it is important to ensure that the user is the ultimate controller of the information/device? If so, why? Would you have any concerns about the user having full control of the device?

Have you considered issues related to *identity* (i.e., *will using a device potentially change a person's sense of her self, of who she is*)? If so, which?

Prompt: Have you considered how the use of your technology may alter individuals' sense of identity? In designing your technology, have you considered issues such as how it *looks* to the end user, how interacting with the technology may alter a person's sense of herself or her *authentic* self, or how it may alter others' perception of her (even as "human")? Is the aim for her to integrate the technology into her identity, or to consider it a tool that she uses, or something else?

Have you considered issues related to *justice* (i.e., *will access to devices be fair*)?

Prompt: How affordable do you envision the BBCI devices being? Have you considered ways that the technology might be made more affordable—even to low-income or low-resource communities—by design rather than as a result of market forces, government assistance, or philanthropy?

Have you considered issues related to what constitutes *normal* functioning and *enhancement* of normal functioning (i.e., where enhanced functioning puts someone at an advantage relative to what most people have)?

Prompt: Some people may prefer not to be "normalized" in the sense of standard functioning. What, if any, of the emerging technologies emphasize such normal functioning? Do you think there are concerns about how the standards of "normal" functioning are created and implemented in this research?

Prompt: Are there concerns about how a standard model of function might apply to a diverse range of people?

Prompt: Do you think of your technology as a form of treatment, or as an enhancement (or does that distinction not make sense in this arena)?

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