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Ethical Considerations for User-Centric iBCI Studies: A Thematic Review

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ABSTRACT:
Implanted brain-computer interfaces (iBCI) have been transformative for patients with paralysis, substantively restoring independent function in key domains. Despite this, the experimental nature and surgical complexity of implants means only 67 patients received long-term implants across published studies between 1998–2023. As the field grows, understanding what users actually want and need from these systems becomes critical to shaping future studies and applications. We performed a reflexive thematic review on the publicly available transcript of 'The Lived Experiences of BCI Users' panel, conducted with three implanted BCI users, identifying 6 key themes: Purpose, Support, Understanding, Connection, Restriction, and Ethics. For each theme we discuss the core ideas with supporting quotes, derive best practice suggestions for future user-centred studies, and compare findings to existing literature, providing insight into the participant experience for researchers without direct exposure to user studies.

INTRODUCTION

The field of implanted brain computer interfaces (iBCI) has seen development since the late 1950s [1], with the first studies being used to map the functions of both animal and human brains. More recent studies within the past 2 decades have focussed on using implanted devices to control assistive technologies, aimed at improving the lives of people suffering motor impairments as a results of amyotrophic lateral sclerosis, high level complete or incomplete spinal-cord injury (SCI) and paralysis after stroke [2]. Although these trials have achieved great successes in controlling prosthesis, decoding imagined speech and generating tactile feeling through cortical stimulation, the limited number of participants in these studies can direct the research involved down a purely neuroscientific or engineering route with the aim of benefitting the user with the broader involvement of the current users or potential user base [3–5]. In this paper, we perform a thematic review of a long form panel discussion with 3 members of the BCI Pioneers Coalition, on the importance and principles of user centric design in iBCI development and deployment [6].

In this paper we aim to answer the research question: what are the most important needs and ethical practices for participants in iBCI studies?

MATERIALS AND METHODS

This study adopts an interpretative, contextualist framework; ethical meaning is treated as socially constructed and context-dependent [7]. Reflexive thematic analysis [8] was selected accordingly. All authors are BCI researchers who facilitated the conversation, introducing potential precommitment to technological optimism. Reflexive discussion throughout analysis ensured themes remained grounded in participant accounts rather than researcher aspiration.

Panellists and Data Collection: Three implanted BCI users from the BCI Pioneers[1] [9] community participated in a semi-structured group conversation. All three were males with SCI: a participant with incomplete quadriplegia from C3–C5 injury implanted with a Utah Array; a participant with cervical SCI implanted with six Utah Arrays; and a participant with C5 tetraplegia whose Neuroport electrode array had since been explanted.
The discussion focused on lived experience with iBCIs, including perceptions of ethical risk, value, access, governance, and legitimacy. Questions and topics were jointly decided between the researchers and the panel members. Questions were open-ended and exploratory rather than hypothesis-driven, enabling the panellists to articulate their own priorities and conceptual framings. The full transcript is publicly available via Zenodo [6].

Analysis Procedure: A reflexive thematic analysis was conducted following Braun and Clarke's six-phase approach [8]. All authors first familiarised themselves with the transcript independently through repeated reading and analytic memoing. Initial semantic coding was conducted individually to capture explicit meaning within the data. Codes were then discussed collectively, and broader patterns of shared meaning were constructed through iterative dialogue. Themes were developed collaboratively, refined through further engagement with the transcript, and finalised during the writing process. Coding was not

[1]https://bcipioneers.org/

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treated as a reliability exercise; interpretation was treated as an active, reflexive process. Consistent with reflexive thematic analysis conventions [8], results and interpretive commentary are presented in an integrated format."

RESULTS

In total, 6 core themes were identified: *Purpose, Support, Understanding, Connection, Restriction,* and *Ethics*.

Purpose: A first core theme identified was the purpose of the implant to the trial participants, and how involvement in research had granted them a new found purpose in life. This purpose is extremely important to the panellists as it is a primary driving force in their willingness to join the study and their continued dedicated participation. One panellist highlighted:

> *"But the potential is giving us participants a new purpose in life, and that's bigger than anything".*

This purpose was especially meaningful to the panellists as it allowed them to specifically work on the technology to help their own rehabilitation and engagement with the world, directly helping themselves.

> *"If you give that person, you're caring for a chance at doing something for themselves, it changes their whole life. That's what I would say about it"*

This sense of purpose was not only restricted to the experiment, but further reinforced by allowing them to revive experiences from their past, previous work, and hobbies:

> *"I've been a musician my whole life—I sing in a punk band. I really wondered if there was any way I would be able to generate music directly from my neuronal activity".*

This highlights the considerable impact on a trial member's life that these implanted devices and projects have, and their ability to provide a purpose not in the present, but connected to the human experience [10]. This aligns with findings from non-invasive BCI studies, in which participation similarly restored biographical continuity and meaningful occupation [3–5].

A further sense of purpose was felt in contributing to the advancement of the field for future users, with active contribution being as important to participants as personal benefit [4]. This altruistic motivation is consistent across invasive and non-invasive BCI user populations [3, 5]; however, a meaningful distinction exists. Non-invasive users framed participation primarily as contribution, whereas iBCI participants here framed it as transformation, a restoration of identity and life purpose that extended well beyond the experimental context.

> *"You have so much pulled away from your life of what you can't do. This is a fantastic opportunity to be able to contribute positively towards not only society in general but also helping individuals who are going through the same things that you're going through."*

Notably, this quote emphasises the panellists' desire to help shape the trajectory of the technology they were implanted with.

Support: A core theme was the need for support throughout the process of the study. The panellists described the support as not only physical due to their condition, but also as forms of direct and indirect psychological support throughout the research process.

Notably, a prominent form of support described was not logistical but relational, moral support derived from researcher dedication.

> *"member of the team in particular, the leader, showed up at the hospital every day just to be there—not doing research, but just building a very real connection"*

Another key support structure discussed by the panellists is the support provided by the family and carers.

> "*I wouldn't be able to participate were it not for my wife, my care partner, being fully engaged in the process."*

This sentiment highlight not only the need for support from the families during the trial, but also how the experimental surgery and experiment process does not solely change the life of the user, but also their wider family [11, 12]. The need for this support is also echoed in a contrasting anecdotal quote recalled by a panellist regarding a family member of another participant:

> *"His mom said, "His brain's the only thing normal left on him, and I'm afraid I'm gonna lose that because they're gonna put electrodes on his brain" ."*

The panellists also highlighted that this support is also required and needs to be guaranteed for a duration of the study. Participants may be reluctant to get involved if they fear the company or lab may go bankrupt. This concern is consistent with researcher-reported consensus that post-trial care obligations extend beyond study completion [12].

> *"Also, what are the ethical considerations behind supporting individuals participating in clinical trials, and what happens long-term for these devices if a company goes out of business or researchers just decide to stop doing the research?"*

Continuous support is highly desirable for all future user-centred iBCI studies. This is reinforced by Pham et al., who found 83% researcher agreement that post-trial care obligations persist beyond study completion, and 82%

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agreement that researchers should develop a nuanced understanding of participants' daily lives including caregivers [12]. That these conclusions were reached independently by researchers, without any end-user input in that study, strengthens the validity of our participants' accounts.

Understanding: Understanding the lived realities of participants is central if BCI research is to meaningfully serve the individuals it is intended to benefit. Discussions with the panellists consistently emphasised that neurological injury, while profoundly altering physical capability, does not alter the fundamental identity of the individual. As one panellist expressed,

> *"Yeah, this is a profoundly altering condition, but this person is still funny, still a pain in the ass, still whatever."*

This observation highlights a persistent tension in the way participants can be framed within research contexts. Participants are often discussed in technical or clinical terms, yet the individuals involved retain the same personalities, social roles, and identities that existed prior to injury. In this sense, the panellists described successful BCI research not purely as a technical achievement, but as work that recognises the continuity of personhood beyond disability [5].

The panellists also described how neural stimulation and sensory feedback delivered through BCIs can rapidly become embodied. Rather than being experienced as an external technological input, these signals can integrate into existing perceptual frameworks. One participant noted that

> *"the stimulation was that close to real life that I didn't even have to think twice about how I perceived it."*

These accounts suggest that when stimulation closely approximates natural sensory patterns, the resulting perception is not consciously interpreted as artificial. Instead, it is incorporated into the participant's existing sensory model of the world. From a design perspective, this reinforces the importance of developing systems that align with natural sensorimotor processing rather than introducing signals that must be cognitively interpreted. This process of sensory incorporation mirrors accounts from non-invasive users who described assistive devices becoming extensions of their own body image [5].

The discussions also highlighted the relational dimension of BCI research. The panellists repeatedly emphasised that productive collaboration depends not only on technical competence, but on researchers developing an understanding of the physiological and social realities associated with severe disability. As one panellist described,

> *"being sensitive to the weirdnesses of a quad[riplegics]'s physiological experience... that level of humanity is important."*

These realities include fatigue, fluctuating bodily states, care routines, and other constraints that shape how and when participation in research is possible. The panellits framed this awareness as a prerequisite for building trust and sustaining long-term engagement within research programmes.

Another theme concerned public understanding of BCI technologies. The panellists argued that demonstrations of BCI capability, particularly those that appear playful or expressive, are often undervalued within academic contexts. One panellist commented that

> *"scientists say it's gimmicky, but that's where people see how your science could be applied in real life."*

From the participant perspective, these demonstrations play an important role in communicating the tangible potential of the technology to wider audiences. They translate otherwise abstract technical progress into applications that are immediately legible outside the laboratory.

The panellists also raised concerns about representation and inclusivity within clinical trials. If participant cohorts are narrow or unrepresentative, the resulting systems risk being optimised for only a subset of potential users. One panellist noted,

> *"We need to make sure we're including a diverse group of individuals within these trials so we're not building models that are one size fits none."*

This is directly supported by Pham et al.'s inclusivity principle [12] and by Kübler et al., who demonstrated that non-invasive BCI systems developed without sufficient user diversity failed to translate into daily use for the majority of end-users, a problem they termed the "translational gap" [13].

Finally, the panellists reflected on the emotional consequences of trial conclusion. One participant described returning to everyday limitations as

> *"a little bit of that loss all over again."*

Kögel et al. documented this structurally: non-invasive users described losing their "job", their team, and their regular outings when studies ended, framing post-trial withdrawal not merely as psychological loss but as deprivation of social participation [5]. Grübler et al. went further, identifying post-trial withdrawal as an established ethical concern, with professionals describing users left feeling useless after weeks of feeling important [4].

Taken together, these perspectives illustrate that BCI research cannot be understood purely in technical terms. The development of these systems is embedded within a broader human context involving identity, embodiment, social relationships, and the lived experience of disability. Recognising and engaging with these dimensions is therefore not peripheral to BCI innovation, but fundamental to ensuring that technological progress translates into meaningful outcomes for the individuals involved.

Connection: A core theme that was focused on by all of the panellists was the connection formed between the

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research team and the participants throughout the trial process.
One panellist felt as if the research team became a new family throughout the research process.

> *"You learn about who's in each other's lives. You can call them anytime. They become your friend, your family"*

This code encapsulates the deep personal nature of participating in an iBCI study [4, 5], and the emotional involvement that is key to the studies success. This connection was not only felt solely with the research team carrying out the specific study. A consistent feature of the discussion was all of the panellists felt connection with the wider research community, whether that would be meeting new people at international events, or as they described:

> *I'm just really grateful that there are all you scientists out there helping figure these out for all the different ailments for all of us*

Our iBCI panellists noted that this broader connection provided not only a sense of purpose, but a sustained source of morale drawn from the collective dedication of a global research community.
Further, connection to the research team and experience also has a positive effect on the participant, even through the difficult periods of the study, including the surgery structure as mentioned previously in support.

Restrictions: A significant portion of the discussion also focused on the current restrictions placed on users with iBCI technologies, including ownership of the equipment and access to the data.
This theme captures how iBCI participation remains institutionally bounded, resource-intensive, and only partially translated into meaningful daily use. Rather than being positioned as personal technologies, current systems are experienced as infrastructures controlled by laboratories, institutions, and trial protocols.
The panellists described limited authority over their own neural outputs.
One noted:

> *I wanted to use it in a recording, and [University] said, "No, we own that."*

Such accounts position data ownership and decision-making power with institutions rather than users, reinforcing asymmetries between participant contribution and institutional control which can be differ globally [14].
Autonomy was further constrained by the structure of clinical trials. As one participant reflected:

> *The only time I'm actively engaged with my BCI is when I'm in the lab… I can't hook in my system on my own. I really wish I could.*

Even with implanted systems, use remains episodic and researcher-mediated, limiting individual benefit beyond experimental sessions.

Participation itself was described as socio-economically selective. Intensive schedules and care needs function as implicit gatekeepers:

> *"I wouldn't be able to participate were it not for my wife… Most quad[riplegic]s require a fairly intense level of personal assistance."*

Access is therefore shaped not only by medical eligibility but by financial resources, care giving capacity, and logistical stability [3, 11].
The panellists also emphasised incomplete translation into everyday life. One articulated the aspiration that BCI should enable

> *"being able to do something that allows you to do what you want to do when you want to do it… and have the BCI really be just a data pathway, nothing more, nothing less."*

This contrasts with current systems that require specialist oversight and custom technical support.
Finally, scaling access was framed as ethically inseparable from privacy protection:

> *Making sure these devices are accessible in a way that you're not giving up too much and not taking advantage of individuals with disabilities…*

Together, these accounts reveal that iBCIs are presently experienced less as autonomous assistive tools and more as governed research devices, with meaningful access contingent on institutional structures and personal resources [3, 13]. A critical distinction from non-invasive literature applies here: Kübler et al. found that non-invasive users were blocked by hardware barriers (setup burden, electrode preparation, transport) [13], whereas the restrictions our panellists faced were institutional and ownership-based. Having already accepted surgical risk, the subsequent denial of data access and independent use represents a comparatively more acute ethical problem.

Ethical Implementation: Lastly, the panellists' call for proactive ethical structuring of iBCI research and deployment. It spans anticipatory governance, neural data sovereignty, structured openness for collective benefit, protection of human agency, embodied surgical risk, and co-design grounded in lived experience.
Panellists described current regulatory frameworks as lagging behind technological capability, positioning governance as a precondition for responsible innovation rather than a corrective after harm occurs:

> *"If regulators aren't thinking about the implications... we're really going to have problems."*

Ethical responsibility was framed as distributed across regulators, institutions, and researchers [12], particularly in embedding privacy and ownership into present data practices.
Neural data were treated as uniquely sensitive and temporally unstable: information collected today may become

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more revealing as decoding advances. This generated concerns around long-term ownership and secondary use, as one participant reflected:

> *"if someone would get that [data] 5 years from now and have more advanced decoding AIs, would they be able to decode my thoughts?... how do we give the user ownership of that data?"*

At the same time, some advocated structured data sharing to accelerate progress given small participant populations, revealing an ongoing tension between collective benefit and durable user control [14]. This tension is quantified in the researcher literature: Naufel and Klein found 58% of BCI researchers supported giving participants access to their raw neural data post-study, yet also felt individuals should be limited in their freedom to donate or sell it, reflecting an institutional possessiveness over data that our panellists directly experienced [14]. Separately, Pham et al. found 90% of researchers agreed BCI data should be shared more widely [12], yet no mechanism for user-controlled sharing was proposed in either study.

The panellists also highlighted the moral weight of invasive intervention. Surgical risk, limited longitudinal evidence on cognitive effects, and the psychosocial impact of device removal extend ethical responsibility beyond initial consent and trial completion.

> *"I wish there were more data available on... what are the cognitive effects of the surgery... there aren't really good longitudinal studies... Is there any potential for negative effects?"*

Finally, co-design was presented as a structural requirement rather than optional consultation, ensuring that devices enhance rather than constrain agency [3, 12, 15].

> *"We can make sure we're developing devices with lived experience and users in mind... that's really going to make a difference"*

Overall, iBCI participation was experienced within conditions of regulatory uncertainty, evolving data power, and incomplete longitudinal knowledge, necessitating anticipatory, participant-centred ethical frameworks.

DISCUSSION

After a full reflexive thematic analysis, we identified six core themes. Purpose emerged as a primary driver of participation, converging with Kögel et al. and Grübler et al. in showing altruism and biographical continuity as central motivations [4, 5], however a meaningful distinction emerged, namely that non-invasive participants described participation as meaningful and our iBCI panellists described it as reaffirming both identity and purpose. This difference likely reflects the greater restorative capacity of invasive systems, but also the higher personal stakes involved where participants had accepted surgical risk, making their investment in the research fundamentally different in kind. Future research teams would benefit greatly from recognising this, and from including participants in the research process as much as possible to produce a development cycle targeting the outcomes that matter most to the people living with these devices.

By extension, support in the manner of clinical, familial, and relational plays a key role in participants' ability to contribute. The dedication of researchers beyond a purely clinical role is an often overlooked source of support. Pham et al. found 82% of BCI researchers agreed that developing a nuanced understanding of end users' daily lives, including their caregivers, was a professional responsibility [12], yet 83% also agreed post-trial care obligations are rarely formalised; a gap our panellists felt acutely. The effect of trial involvement on the wider family is equally important: Versalovic et al. found that for some users, concerns about social stigma and the burden of adjustment led loved ones to question whether functional benefit outweighed the cost [11]. The panellists in our review described their research teams as new families, a finding corroborated on the researcher side by Grübler et al. [4] and mirrored in non-invasive populations [5], suggesting that this depth of relational bond is a consistent feature of long-term BCI participation rather than incidental to it.

Understanding was our broadest theme, and arguably the one with the most immediate implications for research practice. Research teams must keep in mind that participants retain the same personalities, social roles, and identities throughout the study. The injury changes physical capability, not personhood. When this is overlooked, participants risk being reduced to data sources rather than collaborators which may corroborate some of the restrictions and ethical concerns that emerged. Equally, participant-defined goals risk being deprioritised in favour of publishable outcomes, a tension that is structural rather than intentional. Notably the incentives of academic research, sometimes do not naturally align with what users most want from their devices, something one must bare in mind when coproducing with end-users. Representative recruitment compounds this, if trial cohorts remain narrow, the resulting systems will reflect only a subset of potential users. Pham et al.'s inclusivity principle and Kübler et al.'s translational gap framework both point to the same conclusion: systems built without diverse user input tend not to generalise [12, 13].

Restrictions on out-of-lab use and data access remain a significant and underaddressed unmet need. The frustration our panellists expressed wanting their BCI to be simply "a data pathway" available whenever they needed it appeared almost verbatim in Peters et al.'s non-invasive cohort [3], suggesting this is a field-wide failure rather than a problem specific to invasive systems. What makes it more acute here is context: our panellists had already accepted the risk of permanent surgery, yet still found themselves unable to use their devices independently or access their own neural data. Kübler et al. showed that

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even hardware barriers alone were sufficient to prevent non-invasive BCI adoption in daily life [13]; our panellists faced institutional barriers on top of these. Access to participation itself is further constrained by care networks and personal resources, meaning the population currently shaping iBCI development may not be representative of those who will eventually need it most [11].

The panellists raised urgent concerns about data regulation at a moment when decoding technology is accelerating rapidly in adjacent fields. Naufel and Klein found that 58% of BCI researchers supported giving participants access to their raw neural data, yet the same researchers felt individuals should be limited in their freedom to donate or sell it [14], a institutional possessiveness that our panellists encountered directly. Separately, Pham et al. found 90% of researchers agreed BCI data should be shared more widely, yet only 54% agreed end users should be part of the research team [12]. That tension, wanting the benefits of user data without full user participation, is precisely what our panellists were pushing back against. Critically, no end users participated in the Pham et al. survey; the present study provides the counterpart that the researcher-survey literature lacks. Our panellists were clear that co-design is not optional consultation but a structural requirement, a position supported consistently across the non-invasive literature [3, 13].

Limitations: This review is based on a single publicly available transcript involving three panellists, limiting both sample size and data diversity. All authors were involved in facilitating the original conversation, introducing potential researcher influence on what was voiced. Findings are not generalisable but are intended to inform and prompt further participant-centred inquiry. Further, all three panellists were male, US-based, English-speaking, and participated in trials at well-resourced institutions with substantial caregiver support. This relatively narrow demographic profile likely reflects the structural selectivity of iBCI trial participation, rather than the broader potential user population. Notably, the panellists themselves acknowledged this selectivity: one panellists described iBCI trial participants as "just the lucky, crazy ones who want to participate,". Findings should therefore be read as reflecting the experiences of highly engaged, resource-supported iBCI users, and may not capture the perspectives of those currently excluded from participation by the very barriers the themes identify.

CONCLUSION

We completed a reflexive thematic review uncovering six themes; Purpose, Support, Understanding, Connection, Restriction, and Ethics. Identifying positive practices and improvements in iBCI studies defined by users themselves. These findings can inform future study designs and provide insight into the participant experience for researchers not directly involved in user-centred work.

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