A DISABILITY-CENTERED APPROACH TO RESEARCH ETHICS OF EMERGING TECHNOLOGY

The Case of Therapeutic Misconception In Brain-Computer Interface Trials

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ABSTRACT

The inclusion of people with disabilities in the development of emerging technologies is a crucial step towards building a more inclusive and equitable future. However, this involvement can be counterproductive if their lived experience and disability-related knowledge are not adequately taken into account. Among other things, their disability "standpoint" may prompt them to perceive the opportunity of participating in experiments of new technology as a shortcut to overcome the persistent barriers that hinder people with access needs from fully participating in life. This thesis examines the risk of having therapeutic misconception – the false expectation that participation in experimental studies will give direct, personal benefits – among people with diverse disabilities, in the specific case of an emerging neurotechnology called implantable Brain-Computer Interface (BCI). By allowing direct connection between a human brain and external devices, this technology is envisaged to be a powerful, innovative assistive tool that grants greater independence for users with disabilities.

Via a public survey distributed to adults with disabilities across Europe, the study found a concerning level of therapeutic misconception surrounding a hypothetical BCI trial. Even with respondents who are already receiving adequate support from their local community and personal relationships, the risk of having exaggerated hope for such experimental trials is notable. The research also attempts to showcase the distinctiveness and value of the disability perspective by exploring the key areas of concern that arise when individuals with disabilities consider whether to adopt a (trial) BCI implant. As one of the few empirical studies that center the voice of people with disabilities in the context of technological development, this thesis highlights the need to reform ethical research practices through the lens of those who have been historically marginalized. More specifically, it underlines the importance of informed consent protocols to actively and meaningfully engage with the lived experiences of vulnerable research

participants. This is vital to ensure that the advancement of scientific knowledge aligns more closely with the practical needs of its intended beneficiaries, while serving the interests of society as a whole, including the most vulnerable groups.

Keywords: disability, research ethics, informed consent, therapeutic misconception, Brain-Computer Interface.

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CHAPTER 1: RESEARCH BACKGROUND AND INTRODUCTION

1.1. People with Disability and Research Ethics

From Epistemic Gap to Research Ethics Involving Vulnerable Groups

For marginalized groups in general and people with disability in particular, technological development can be a field heavily laden with layers of political complexities. Inter alia, this is because when innovations and applications of scientific knowledge are designed to serve the interests of the many without due consideration for the few, they can become a vehicle that further entrenches exclusion and discrimination. In contrast to the idealistic view that technology is mere mechanics devoid of human subjective judgements, a growing line of scholarship has exposed how these supposedly unbiased tools can carry on the existing prejudices, however hidden, of their creators. For the simple reason that they are built upon datasets that fail to properly represent many minority groups, technologies can unknowingly perpetuate discriminatory, harmful biases. In the context of race, for instance, this issue has been explored by Ruha Benjamin as she discusses examples of data-driven systematic discrimination such as the infamous Google Photos incident of 2015 when a black couple was labelled as gorillas by image labeling algorithm (Benjamin 2019). Or in the context of gender, Caroline Criado-Perez's well-known book "Invisible Women" has exposed how various types of technology – from farming and military tools to personal protective equipment – have been designed with a typical male figure in mind that they can create safety hazards for female users (Perez 2019). For the disability community, the experience of systemic discrimination resulting from insufficient direct input is just as severe, if not more so.

In fact, it is not an overstatement to say that this has been a crucial part of the story behind the disability community's long-standing struggle against ableist social arrangements

that are often designed only for, and by, the able-bodied majority. Most recently, for a revolutionary solution extensively adopted nowadays that is artificial intelligence (AI), it has been increasingly reported that AI-based systems discriminate against individuals with disabilities at various stages of the job application process, from automated CV screening to interviewing (Glazko et al. 2024; Nugent and Scott-Parker 2022). Even innovations specifically built to assist different needs can embody ableist assumptions that overlook the realities that people with disabilities live with. For instance, the idea of an augmented cane that can detect obstacles from afar and instruct blind users how to move around, while sounds ideal, may cater only to the fantasies of the non-disabled designers. This technological application does not work for its target audience because, as explained by a blind person, the designers have completely ignored the fact that the $400 price tag for this smart cane is not at all "affordable" for the limited disability benefits that blind people receive, especially considering that the classic, less heavy white cane can identify obstacles just as well and is provided for free (Bidleman 2021).

At the heart of the disability community's demand for a more inclusive society is, therefore, a strong emphasis that their expertise should be consulted in every discussion that affects their life. A significant milestone in that regard has been the development of the UN Convention on the Rights of Persons with Disabilities (2006), the first human rights convention with the direct participation of people with disabilities at the negotiating table. Just as technology built on biased data can generate detrimental repercussions for the excluded groups, innovations created without adequately considering the varied experience of individuals with disabilities may inadvertently uphold existing patterns of ableism. Acknowledging this challenge in the development of new technology[2], international guidelines have directed more attention to the importance of encouraging and facilitating the participation of diverse

[2] Throughout this study, "new technology" and "emerging technology" are used interchangeably to refer to recent technological innovations, especially those with the potential to transform society in various ways.

populations, including those with different needs. The UNESCO's draft Recommendation on the Ethics of Neurotechnology, though not yet published at the time of writing, has dedicated specific provisions to address this issue of epistemic justice (point 59) and meaningful consultation with people with disabilities (point 144) (UNESCO 2025).

It is indeed a much-needed step to include disadvantaged groups in research of new innovations, both to gradually dismantle the deeply seated structures that marginalize them and to produce practical solutions that actually benefit everyone. However, at the same time, involving people with disabilities or other vulnerable populations[3] faces a conundrum in research ethics – also known as the inclusion-protection dilemma – that is no less of a political issue: they may be exposed to additional harm because of their own vulnerable backgrounds (Schroeder et al. 2024; Friesen et al. 2023). Although the debate over the appropriate safeguard is still ongoing, research projects involving (vulnerable) human subjects nowadays typically must comply with a plethora of ethical standards to ensure that the participants' involvement is both meaningful and conducted safely. In part, this is a result of a long, troubling history in which many vulnerable groups – from institutionalized children to black men (with the infamous case of the Tuskegee Syphilis study) – were exploited in the name of advancing new knowledge (Dhai 2014). Today, the field of research ethics and bioethics in general are committed to ensuring responsible research conduct so that human dignity, rights, and well-being remain central to all scientific advancement.

Before ethical research standards were taken seriously as they are now, the landmark event that marks the turning point for modern bioethics came with the disclosure of the

[3] There is also no unified approach to defining "vulnerability" in the discourse of research ethics or bioethics (Bracken-Roche et al. 2017, Schroeder et al. 2024). This thesis proceeds with the premise that people with disabilities constitute a vulnerable population in research because of their status as an undervalued, marginalized social group – which might make their voice less valued and make them more susceptible to exploitation in research context (B. G. Gordon 2020).

scandalous, unlawful experiments done by the Nazi on concentration camps prisoners. The Nuremberg Code (1947), in light of these revelations, was established to set out some ground rules for future human experimentations. Foremost among its core principles was the requirement of "voluntary consent" which necessitates that involvement in research must be an exercise of the participant's absolute free will, free from undue influence and with full disclosure of the study's details. This concern for consent was further substantiated with the birth of yet another influential ethical code, the Declaration of Helsinki (1964), crafted by the World Medical Association. The declaration not only helped advance the "informed consent" concept but also opened the door for more inclusive research environment by allowing proxy consent from legal representatives in cases where participants are incapable of giving consent themselves. Since their inception, both the Nuremberg Code and the Helsinki Declaration have been among the most influential codes of ethics guiding the development of ethical protocols across the globe.

In parallel with the growing recognition of the importance of involving historically marginalized groups outlined above, the Declaration of Helsinki has been frequently revised to finetune its protecting power in the face of new challenges unfolded by the rapid advancements in scientific research. In its latest eighth update (October 2024), some critical changes have been introduced. While the 2013 revision has already expounded the requirement for informed consent in much greater detail than its predecessors and acknowledged that vulnerable groups may incur additional risks due to their unique life circumstances (World Medical Association 2013), the 2024 version takes the emphasis on actively listening to these vulnerable groups a step even further. Signaling that informed consent is not a mere procedural formality that records participants' voluntary agreement to take part in the study and that they are provided with the necessary information, it now emphasizes the need for "meaningful engagement" with the participants and their community throughout the research project (Article 6). Besides that,

there are also noteworthy modifications with its language and scope. The terminology "research subjects" has now been replaced with "research participants", while its recommendation scope has been extended from physicians to include any individuals or bodies involved in the research projects, making the document applicable to a wider range of stakeholders and disciplines (World Medical Association 2025). By so doing, these transitions have at the same time broadened the declaration's sphere of influence and reflected a critical shift towards more participatory, people-centered research practice that values the ultimate agency and lived experiences of (vulnerable) participants. Above all, these modifications have attested to the epistemic issue of sidelining the voices of marginalized groups and called for more attention to how the experience distinct to their life circumstances may affect the quality of their consent. The thesis further investigates this interaction between one's background as a member of a vulnerable population and the likelihood of compromising their informed consent, paticularly by falsely equating participation in experimental study with receiving medical care. This false understanding, defined as therapeutic misconception, is particularly relevant in the context of clinical trials that develop new assistive devices for people with varying accessibility needs.

Therapeutic Misconception: A Threat to Informed Consent in Clinical Trials

Generally speaking, therapeutic misconception (or therapeutic misperception) occurs when a participant in experimental studies or clinical trials confuses the experimental nature of the research and conflates it with the opportunity to receive individualized (medical) treatment. When that is the case, this misinterpretation can impair the participant's informed consent as their involvement is basically premised on false hopes. More gravely, it may also prompt them to underestimate the risks involved and have an inflated view of the perceived benefits of participating in the trial (Lidz et al. 2004). To avoid this problem, it is thus essential to ensure

that participants clearly understand the crucial difference between clinical trials and normal medical procedures.

The key distinction between the two is that unlike standard medical treatment which prioritizes individualized patient care, clinical trials are designed to generate generalizable scientific knowledge. As a result, the ethical obligations owed to medical practitioners and clinical researchers differ radically. While medical practitioners primarily focus on promoting the patient's well-being, experimental studies researchers – committed to the specific objectives of their scientific projects – are oriented towards generating valid and generalizable data. This means that in clinical trials, participants' interests may rightly take only secondary role to the project's goals, and they may not receive the best *treatment* for their conditions by participating in the trials. Instead, clinical trial participants are expected to follow the research procedures they have agreed upon, whose end goal is to serve the research project itself and not necessarily to benefit the participants (Appelbaum et al. 1987; Lidz and Appelbaum 2002).

For people with disabilities, the issue of conflating research with treatment might be particularly concerning in trials developing assistive technologies, as hope for improved quality of life may cloud their judgment about the experimental nature of the project at hand. In a hostile and ableist environment, people with disabilities might be disproportionately prompted to seek out such trials, not out of genuine choice but due to a systematic deficit of alternative accommodations for people with diverse needs and capacities. A case in point to examine this effect is the trials of implantable Brain-Computer Interface (BCI), a promising assistive technology currently tested exclusively on disabled people. BCI will also be the case study this thesis focuses on to study the risk of therapeutic misconception among this vulnerable population.

1.2. Case Study: Therapeutic Misconception in Implantable BCI Clinical Trials

In simple terms, BCI is a technology that picks up the human's neural signals and translates them into direct commands of an external device (such as computers, robotic limbs, text-to-speech machines, etc.), depending on the specific users' needs. This means that so long as the user's neural activity is still active, BCI can be a powerful assistive device that allows people with disabilities, including those with locked-in syndrome (Schmid et al. 2021), to use their thoughts to control a device substituting for their impaired functions. Because of its transformative potentials, BCI are widely perceived as a cutting-edge technology that can potentially help overcome many types of physical impairments. While BCI applications can also be noninvasive (in the forms of wearable devices), this thesis focuses specifically on invasive BCI (i.e., implantable BCI) – those that involve a surgery of some sort to insert electrodes/chips inside the human brain. This specific type of BCI is a better focus for the current research project, because unlike noninvasive BCI, no implantable BCI thus far has been officially introduced in the market, and its utilization and development remain restricted within research settings.

From the first project that received the green light to proceed to clinical trial in 1998 to 2023, there have been 21 implantable BCI projects across the world, conducting or having conducted a total of 28 clinical trials with 67 participants (31 of which are still active)[4]. Out of the 28 trials, 18 are done in the US, followed by 7 in Europe (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024). The main usage of BCI in these trials are to facilitate or restore control over muscle, speech and the sensory functions. Up to this day, all the executed BCI clinical trials have been done on people with severe disabilities, ranging from people with impaired

[4] This number does not include trials that are a/ neither published nor covered by the media by December 2023 (including Neuralink's clinical trial pronounced only in early 2024); and b/ short-term studies.

sensory functions to those with brainstem strokes or diagnosed with Amyotrophic Lateral Sclerosis (ALS) (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024).

Implantable BCI offers a particularly compelling case to study from a disability perspective because this is an instance where people with disability, perceived to be the main beneficiaries of this new technology, have been put as the focal point of the development process. On top of that, BCI is currently a highly topical issue. While considerable public attention has been drawn to recent developments in BCI projects, especially after the emergence of private brain chip companies such as Elon Musk's Neuralink (Almanna et al. 2025), scholars have also raised concerns for the technology's far-reaching ethical implications – ranging from brain data privacy to threats to social identity – that may go beyond the scope of existing guidelines and regulation frameworks (Hosseini and Kumar 2020). As of now, China is the only country with an official guideline on BCI study (The Artificial Intelligence Ethics Subcommittee of the National Science and Technology Ethics and Commission 2024), while a UNESCO comprehensive recommendation on ethical neurotechnology research and application is expected to be published only by the end of 2025 (UNESCO 2025).

The first question this thesis investigates is the presence of therapeutic misconception among people with disability when they consider BCI trials (research question 1 – **RQ1**). In so far as this technology aims to enable people with disabilities to regain more control in several aspects of their daily life, something many would fight for years to be able to achieve through social accommodations, the hope of gaining personal benefits from being a tester of such technology can be a powerful incentive. Furthermore, digging into how one's experience of life with disability informs their misperception (or lack thereof), the second question that this research explores is whether the risk of therapeutic misconception is positively related to a person's access to a quality support system (**RQ2**). Additionally, to further illuminate the

nuances of the disability perspective, the thesis also conducts an exploratory analysis to see what key issues people with disabilities associate with BCI clinical trials.

1.3. Research Significance and Outline Overview

This research contributes to the ethical involvement of people with disabilities in the development of emerging technology, especially during the clinical trial phase, in at least two aspects. First, by adopting therapeutic misconception as the analytical lens, it directly enriches the body of literature aiming to improve the consent procedure. If a notable level of treatment misconception is identified within the study sample, BCI researchers need to better engage with the trial participants and ensure that they do not have a distorted understanding of what the experiments would entail. As elaborated at the beginning, addressing this type of misconception is crucial in managing expectations and facilitating effective informed consent. Although the research subjects of this thesis – individuals with diverse types of disabilities – may not be directly involved in current BCI clinical trials and may not necessarily consider doing so, their input can still offer valuable insights into how people with disabilities view trial studies of new technology.

Second, this study does not only just bring the perspective of people with disabilities into the spotlight, it does so at a critical time when the development of this game-changing technology has garnered a lot of public attention. While invasive BCI to date have been designed for therapeutic use (i.e., addressing certain medical conditions) and primarily targeted people with severe disability, many have speculated about the several applications of the technology by non-disabled people, for purposes ranging from pure entertainment to enhancement of normal human capacities (Graceshalini, Rathnamala, and Prabhanantha Kumar 2023; Valeriani, Cinel, and Poli 2019; E. C. Gordon and Seth 2024). Beyond the question of

safeguarding informed consent of those involved, the chosen focus of implantable BCI trials thus allows us to learn more about the perspective of those who approach this cutting-edge technology as an assistive device to overcome daily challenges, rather than as a recreational tool. Testing implantable BCI devices on people with severe disabilities is typically justified on the premise that this group is the primary beneficiary of a technology envisioned to help them regain control over bodily movement. However, considering the multiple other potential applications of BCI beyond addressing accessibility needs, this research also seeks to highlight the political responsibility that is required when vulnerable groups are beta testers for a technology poised for later mass adoption.

Following a brief summary of the thesis's context and structure, the second chapter presents the thesis's two underlying theoretical strands – standpoint theory and therapeutic misconception. Whilst the former helps highlight the exclusive expertise that only people with disabilities can offer, the latter provides an operationalizable framework on which this knowledge can be drawn. This chapter also provides a comprehensive overview of the existing literature on therapeutic misconception and explains why similar endeavors should be done in the context of BCI-related trials. Then, before explaining how this research adapts Appelbaum et al.'s original framework to measure therapeutic misconception, the research design chapter details how the survey is designed and distributed to nearly two hundred disability-related organizations in Europe to collect data. Via descriptive data analysis of the 32 responses submitted by adults with motor, sensory, and communicative disabilities, the study found that the risk of having therapeutic misconception, and therefore potentially compromising their consent in implantable BCI trials, is prevalent among people with disabilities. Though there is no evidence that lacking decent accommodation from the surrounding environments would encourage respondents to hold higher hopes for the trial, a majority of those who believe in the independence-enabling benefit of the trials in fact enjoy a very good support network. Besides

the differing opinions on the advantages of BCI for individuals with disabilities, the exploratory thematic analysis also reveals two other prominent themes among the respondents when they discuss the appeal of joining in a BCI clinical trial: concerns for risks and emphasis on respecting the prospective disabled person's autonomy in deciding whether or not to take part in the experimental study. Reflecting on these findings, the thesis concludes with some practical suggestions to refine the consent procedure in research projects involving people with disabilities and lists out some limitations in the current research that future studies can build upon.

CHAPTER 2: THEORETICAL FRAMEWORKS

2.1. Standpoint Theory

The underlying reason for my emphasis on listening to the expertise of the disability community, as well as other marginalized groups, is grounded in the logic of standpoint theory. For the rest of this research, this theory will inform the research more from the background and let therapeutic misconception take the stage. Nevertheless, it is worth introducing its central tenets and how this critical theory is relevant to the current discussion on BCI clinical trials.

Rooted in the Marxist tradition and subsequently taken up in feminist discourse, standpoint theory posits that members of marginalized groups possess a kind of exclusive, "situated" knowledge (Haraway 1988) that is shaped by their specific group's experience of being disadvantaged by the dominant social institutions. This knowledge in turn grants them an "epistemic advantage" in viewing the world, especially in matters that concern the systems and power dynamics that marginalize them in the first place (Anderson 2024; Crasnow 2014). Arguing that knowledge construction is closely tied to socio-political context, standpoint theorists contend that marginalized groups, with the lived experience of being on the margins of society, can illuminate what perspectives are overlooked or hidden from the (plain) sight of the dominant majority. Without the direct input of these muted voices, any generated knowledge would only be a myopic view of reality.

Notwithstanding its controversial elements – such as the emphasis on the *exclusive* knowledge available only to the minority groups, or the objection to objective knowledge (Anderson 2024) – standpoint theory remains an influential school of thought in inspiring more inclusive research practices. A standpoint research framework is one that prioritizes more participatory approach, starting from the bottom-up, to decolonize the reservoir of knowledge

that is often shaped, and to certain extent distorted, by the dominant groups (Harding 2003; Wylie and Sismondo 2001). With the same logic, disability bioethics has openly criticized mainstream bioethical frameworks' for neglecting the valuable insights of disabled people and thereby often failing to account for the unique experience of life with disabilities (Mor 2018; Ouellette 2011). Situating the critique of bioethics against the famous slogan of disability activism – "Nothing about us without us" – Sagit Mor has highlighted how the absence of people with disabilities from the decision-making process has resulted in the heightened medicalization and paternalization of disability in bioethics practices, which further prevents them from contributing a realistic account of life with disabilities and the values of disabled people themselves (Mor 2018). Fostering "disability-conscious bioethics", in Ouellette's words, entails building a research framework that "works for – and with – people with disabilities" (Ouellette 2011, 316).

Since assistive technologies are not designed to be used in a vacuum but in constant interaction with the surrounding environment (Frauenberger 2015), it is even more important that people with disabilities are directly consulted in the assessment of their practicality and effectiveness. While other experts (such as medical doctors, researchers, etc.) may have different things to consider in the development of a new technology, a device primarily designed to serve disabled users should pay more attention to the perspective of those who actually will use it and have rich experience in navigating environments not designed for people with different needs. This holds true even for technology that most people have not had the chance to experience, such as implantable BCI, since people with disabilities can still reflect on their existing knowledge and provide a credible "situated imagination" that is not any less valuable (Stoetzler and Yuval-Davis 2002). The additional thematic analysis towards the end of this research leverages this perspective to give people with disability an opportunity to give testimony for the most salient concerns that come to their mind when they think of BCI trials.

As standpoint theory affirms that people with disability are indeed the true experts on disability-related matters, the connection between standpoint theory with the current research is therefore straightforward.

2.2. Therapeutic Misconception

Conceptual Framework

While standpoint theory provides the foundation on which the thesis can direct its focus on the perspective of those with disabilities, therapeutic misconception is the main theoretical map that guides the research project at hand to answer its key research questions. Premised on the crucial distinction between treatment and research outlined in the introduction, therapeutic misconception can be broadly construed as the mistaken belief held by participants of human-subjects research that the clinical trials they are involved in, similar to a medical procedure, are designed to provide them with direct, tailored benefits. The concept started to gain widespread attention in 1982 when Paul Appelbaum and colleagues identified and highlighted the noticeable anticipation of therapeutic gains among study participants in the context of psychiatric research (Appelbaum, Roth, and Lidz 1982). Since its publication, this seminal work has spurred a growing body of literature that seeks to understand the nuances of this phenomenon across various research fields and study populations.

Although there is no widely adopted definition of therapeutic misconception, there is a broad consensus among scholars that this problem is endemic in clinical research and can manifest in three types of false beliefs – which constitute the three interrelated dimensions of therapeutic misconception – regarding: the *individualization* of treatment, the trials' overall *purpose,* and the *benefits* of participation (Appelbaum et al. 2012; Jansen 2020). With respect to the first one, people may mistakenly assume that the trial, as well as the treatment they are

administered, is specifically designed for their unique personal needs. The second dimension, a misbelief also directed towards the trial's design, is brought to light when people believe the chief objective of the trials is to serve the interests of the participants, instead of generating generalizable scientific knowledge (and therefore primarily serve future users). Finally, the third facet of therapeutic misconception pertains to the inflated expectations that participation will accrue direct benefits from the trials (Jansen 2020; Appelbaum et al. 2012).

As for its causes, therapeutic misconception can be attributed to several factors, both internally and externally to a specific trial's details. When Appelbaum et al. first explored the phenomenon in 1982, their research findings confirm that participants' adequate understanding of the trial's protocol and methodology – such as whether the treatment will be randomly assigned, or if a placebo will be used – will help them better manage expectations for the trial and less likely to have therapeutic misconception (Appelbaum, Roth, and Lidz 1982). Yet, at the same time, the study also signals the multifacetedness of therapeutic misconception by revealing that even when the study subjects fully understand the methodologies, some traces of misconception are still evident. As subsequent studies have shown, misperceiving the nature of a clinical trial is not solely a matter of misunderstanding the project's terms and conditions but can also result from the manifestation of several factors outside of the research's settings. These could be the biased cognitive framing that impels the participants to think more of their own conditions (Lidz et al. 2015); the relationship dynamic with the trial investigators (Charuvastra and Marder 2008); the perceived paradigm-shifting impact of the technique or technology at hand, as in the case of gene therapy (Churchill et al. 1998); demographic features such as education level, gender; or the severity of their conditions (Durand-Zaleski et al. 2008; Thong et al. 2016). Continuing this line of investigation, the second question that my thesis aspires to inspect is whether the surrounding environment can increase one's pressing needs for new therapy and thereby distort their interpretation of what a clinical trial is meant to do. In the

specific case of disability and BCI trials, I hypothesize that lacking comprehensive accommodation, either from public accessibility support or personal relationships, might make people with disabilities more susceptible to misinterpreting experimental studies as an opportunity to minimize the impact of their disability and thereby have higher therapeutic misconception (**H2**). As for the first question, based on the available information surrounding existing invasive BCI trials outlined below, misperception risk is also expected to be widespread (**H1**).

Before explaining the basis of my assumptions, some technical clarification needs to be made here. First, throughout this research, the *therapeutic* benefit associated with BCI trials should not be understood rigidly as a cure for one's specific medical conditions or impairments. Rather, "therapeutic" is only used as a technical term for the research to remain consistent with the literature on therapeutic misconception, and should be read in a broader, non-medical sense, referring to the independence-enhancing benefit of BCI. Arguably, this is also where the primary attraction of this new technology lies. By improving or restoring functions like movement, sensory perception, or communication, BCI-based devices seek to enable users to have greater control over their daily lives and interactions. Even from the developer's perspective, BCI is believed to have direct effects on disabled users' autonomy (van Stuijvenberg et al. 2024). By the same token, hereafter "treatment" is also not strictly about the medical care given to alleviate a specific health condition. Rather, in most cases, it is a technical term in clinical settings that refers to the intervention (or the independent variable wished to be tested) assigned to a trial participant. Depending on the trial's design, it is possible that participants in clinical trials effectively receive no treatment because, for instance, they are assigned a placebo or randomized into the control group. However, because of the implant required for the BCI device, it tends to be the case that all volunteers receive a device and train with it (i.e., no participants are *untreated*). As the next review of existing literature on invasive

BCI trials will demonstrate, this is one of the reasons that heightens the risk of misreading the trial's intent.

Literature on Therapeutic Misconception in BCI-Related Trials: An Empirical Gap

Reflecting on the evolution of therapeutic misconception 25 years after its introduction, Kimmelman (2007) notes that while the concept originated in the context of psychiatric medicine, it has been taken up in early-phase trials of cancer treatment and other fields. Till this day, it seems that psychiatry and oncology remain the dominant grounds for studies of therapeutic misconception, and research in the young field of neurotechnology has been sparse. With an increasing number of BCI trials in the pipeline, therapeutic misconceptions in BCI-based clinical trials have also drawn more attention in scholarly discourse. The area closest to implantable BCI where therapeutic misconception has been studied is that of deep brain stimulation for depression patients who are resistant to standard medical intervention (Fisher et al. 2012; Leykin et al. 2011). Drawing on the early days' experience of deep brain stimulation to canvass the ethical challenges awaiting for invasive BCI, Klein (2016) has identified false expectations, and by extension – therapeutic misconception – as one of the six risk areas that threaten valid consent in BCI trials[5]. A later scoping review of the technology's key ethical issue would show that Klein's unease with high hopes for BCI is shared by many others (Burwell, Sample, and Racine 2017). More importantly, the review also indicates that these speculations remain largely theoretical and conceptual and would benefit from concrete empirical evidence.

The need for a data-driven investigation of false therapeutic assumptions is even more pressing given that many of the factors believed to activate this misbelief are rife in the realm

[5] The other five risks concern safety, cognitive and communicative-related disabilities, effective voluntariness, mood disorder, and data security (Klein 2016).

of BCI study. While Klein's (2016) assessment has warned about the problem of limited availability of information on previous BCI trials, this is still very much a live issue today. In spite of the fact that the first BCI clinical trial was conducted nearly three decades ago, research projects in the field continue to lag behind in producing up-to-date reports about their progress and results. On average, it typically takes about two to three years for a case to be published after the participant receives the BCI implant (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024). This is an issue that should not be taken lightly, as it can trigger a series of even more serious problems, including, for instance, the lack of comprehensive reporting on the actual benefits of being a participant in BCI clinical trials. Per week, participants are normally expected to spend two to four sessions, amounting to approximately 6-16 hours weekly to undergo specific tests that are not directly related to daily living activities but are primarily meant to assess the functioning of the technology (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024). This means that not only do the actual benefits of participating in clinical trials remain an open question, but also the effectiveness of the technology in assisting disabled users with daily tasks has yet to be proven. All the while, the open-ended nature of BCI's trial – where each participant is assigned with a specific device that continuously gets customized over time – might even induce participants to characterize it more as a personalized intervention (Klein 2016).

One can argue that the problem of limited information availability is not distinct to BCI experiments but is an inherent characteristic of clinical study. There is not much information available simply because by definition, clinical trial is a first-in-human test of a new drug or medical treatment that has passed some minimum thresholds for safety. In a limited number of compassionate use programs, some people with serious terminal conditions are even allowed to try out unapproved medicines when they have exhausted all other alternatives (European Medicines Agency 2009). However, the story is quite different when in the face of such

informational lacuna, there is a heightened interest around BCI projects (Burwell, Sample, and Racine 2017). Especially with the entry of private companies such as Synchron and Neuralink into the BCI trials landscape alongside other academic-related projects, growing public attention is evident in both the media (Beck, Liberman, and Dubljević 2024), and public discussion on social media (Almanna et al. 2025). When one looks up the key word "BCI trial" on the Internet, it is not hard to come across feature stories of how the trial implant has successfully allowed people with ALS to "speak again" (Yehya 2024), or to "control Amazon Alexa (a virtual assistance) with their minds" (Mullin 2024). As much as these are welcome news, it is concerning that there are only a few trustworthy reference materials available for the public to cross-check information and understand the story in its entirety. Because of that, even before considering the potential benefits of this technology for people with disabilities, the risk of having distorted perceptions of BCI trials is already likely to be substantial (H1).

Support Network and Therapeutic Misconception

Since the overarching benefit that implantable BCI offers is the restored control in a disabled person's life, the opportunity to take part in BCI trials might be particularly appealing to those who have a more urgent need for that independence or believe that they cannot achieve that level of independence through other means. To some extent, this argument can be considered an equivalence to an established finding in the existing therapeutic misconception literature which indicates that lack of alternative medical treatments and severity of illness all contribute to a higher degree of therapeutic misconception (Durand-Zaleski et al. 2008; Dunn et al. 2006). More related to the appeal of independence, it has also been suggested that people who had to rely more on *others* for their daily functioning are more prone to therapeutic misconception (Thong et al. 2016). Particularly in the independent living philosophy of people with disabilities, this "others" can be understood as a broad network encompassing both the

accommodations provided by a person's neighborhood and relationships (Hasler 2003). The second research question that will be explored is, therefore, whether a person's expectation for BCI clinical trials is inflated by their access (or lack thereof) to such quality support system.

With the same focus on vulnerable populations and on the constraints of specific life circumstances, a study using a roughly analogous approach to this current research was conducted on incarcerated individuals in 2016 (Christopher et al. 2016). By interviewing 72 people confined in correctional facilities about their expectations for clinical trials, Christopher and colleagues have found a particularly high degree of therapeutic misconception in this unique setting. More importantly, they also discovered that a significant number of inmates believed that due to the limited treatment options available behind bars, clinical trials were the only way for them to get the necessary medical cure. One may similarly posit that due to the considerably inaccessible environment they live in, some people with disabilities may perceive participation in trials of assistive devices as one of the very few options for them to lead an independent life. In other words, the risk of therapeutic misconception on BCI trials might be higher among people who lack viable alternative accommodations (H2).

At first glance, this consideration for one's relationships with the surroundings might appear to mirror the argument of relational autonomy theorists. Across its various formulations, the core idea behind relational autonomy is that individual's agency is deeply embedded in a complex web of connections with others, such that their reasoning capacity, and with it every decision that is made, is never truly free from external influence but in part a byproduct of that multidimensional interdependency. On this view, a person's autonomy is ultimately shaped by the virtue of their social relationships (Liu et al. 2022; Stoljar 2024). Although my hypothesis shares this concern for the broader context in which a person's life is situated, its understanding

of independence[6] is much narrower. Since the form of control BCI technology could produce is mainly functional, targeting specific tasks such as communicating or using the computer, the independence that it offers is strictly *physical* and refers to the ability to carry out activities without (much) external assistance. What is meant by "support network" in this study is therefore the physical and social accommodations that can help a person with disabilities be as independent in their daily life as possible.

Having laid out the theoretical frames and key concepts that inform this research project, the next chapter turns to the data collection method used to examine the following two main hypotheses and the complementary exploratory investigation:

H1: There is a heightened risk of misunderstanding the purpose and nature (i.e., having therapeutic misconception) of BCI trials among people with disabilities.

H2: Individual with disabilities who lack access to a robust support network (support from their local environment and their personal relationships) are prone to having a higher degree of therapeutic misconception on trials of assistive devices such as BCI.

Exploratory investigation: What are the key concerns that people with disabilities identify when they consider the opportunity to participate in BCI clinical trials?

[6] I understand autonomy and independence as two interrelated but distinct concepts. While the former refers to a person's ability *to make decisions* without external constraints, the latter refers to the ability *to act* on one own without any external help (Liu et al. 2022).

CHAPTER 3: RESEARCH DESIGN AND DATA COLLECTION

Empirical data for this study were obtained through an English survey conducted online and administered to more than 170 organizations and associations for people with disabilities across Europe. This method of data collection is not only cost-effective for a research of this scope, but it is also a suitable approach to gather insights from people with disabilities who reside across many different European countries and have diverse needs. Setting the scene for the subsequent analysis, this chapter provides a detailed, transparent explanation and justification behind the survey's design, its target audience, dissemination strategy, as well as how ethical considerations were factored into its setup. In terms of structure, the questionnaire consists of four main parts: the first gathers background information of the respondents, including their types of disabilities; the second evaluates the risk of therapeutic misconception in a hypothetical case of implantable BCI trial; the third, serving the exploratory investigation, probes general opinion about the trial; and the last assesses the quality of the respondents' network of care and support. To view the complete survey, refer to Appendix 3 or Appendix 4 (plain language version).

3.1. Target Population and Sampling Strategy

Provided that BCI is specifically designed to support needs in movement, processing sensory input, and communication, the target audience of BCI project has mainly been those with motor, sensory or communicative disability (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024). To reflect the group of people typically targeted for BCI trials, the survey is for adults (aged 18 and above) residing across Europe who identify themselves as a person with motor, sensory, and/or communicative disability. Although admission to actual BCI trials depends on various other factors (such as medical conditions, personal compatibility,

geographical distance, etc.), this group of respondents can be considered a potential pool of future candidates for BCI trials. Even when many of them do not consider participating in such trials, their experience of living with the relevant types of impairments may still provide valuable insights to fine-tune the recruitment and research protocols of future trials. How this sampling strategy is suitable for a study on therapeutic misconception in BCI trials will be elaborated in fuller detail in this chapter's third section, where categorization of disability types is explained.

Respondents were recruited via purposive sampling. An article[7] calling for participation in the survey was posted on the European Network on Independent Living, a Europe-wide network of people with disabilities. Email invitations were sent to 176 organizations and associations of people with disabilities, neuromuscular disorders, spinal cord injuries, or brain injuries, etc., across Europe[8]. The strategic decision to concentrate on a specific region (albeit the geographical scope of this "European region" is only a rough estimate) is intended to ensure that most survey respondents share a relatively comparable socio-political background and are subjected to generally similar legal frameworks and human rights protection standards.

3.2. Ethical and Accessibility Considerations

As all participants involved in this study are people with disabilities, careful consideration is given when designing the survey. The research plan for identifying participants, obtaining consent, as well as storing and using the acquired data was approved by the Ad-hoc Ethical Research Committee of the Political Science Department at Central European University (Appendix 1). The issue of mental competence is not particularly salient for the

[7] "The Right Way to Develop Neurotechnology – Share Your Insights!" (last accessed: 30 May 2025).
[8] See Appendix 2 for the full list of all contacted organizations.

research at hand since the survey mainly targets participants with motor, sensory or communicative disabilities. However, I acknowledge that there might be cases in which the types of disabilities specified above also entail certain complications that compromise a prospective participant's capacity to give autonomous, effective informed consent and/ or require additional consent from their legal representative. It was therefore up to the participants to interpret, based on their own country's legal framework, whether additional consent from their representative or decision-making support is needed and ensure that they readily had the representative's explicit approval, or the needed support to give consent and participate in the survey. With regards to accessibility, there is an alternate version of the survey available in plain languag[9] (Appendix 4). This version follows the rules of Inclusion Europe's "Information for all: European standards for making information easy to read and understand" (Šveřepa 2021), which is designed to support those with reading difficulties, including individuals with intellectual disabilities. Participants with other accommodating needs could contact me and reasonable adjustments within my capabilities could be arranged upon request. The survey was tested and consulted with some disability experts before its official launch.

3.3. Survey Questions

Demographic & Disability Questions

Information regarding age group, country of residence, gender, and education level was gathered through a set of standardized, multiple-choice questions proposed by Qualtrics. Disabilities are categorized into three groups, in line with the three areas of functioning that implantable BCI is designed to address: motor, sensory, and communicative. Motor disability is generally understood as limited muscle control and movement of one or more body parts. A

[9] This accessible survey format is referred to as "plain language" rather than "easy-to-read" simply because it has not been checked by a person with intellectual disability.

disability is classified as sensory when it concerns senses, such as vision, hearing, touch, taste, or smell. Lastly, communicative disability refers to the inability to exchange and understand information (either verbal or non-verbal).

In this research, the nature (or type) of disability is completely determined by the respondents, rather than their specific medical diagnoses. This means that for the rest of this study, if a person is referred to as a person with motor/ sensory/ communicative disability, it is because he or she has indicated so in the questionnaire, even when other people possessing the same medical conditions with him/her may have identified themselves differently. The pragmatic reason behind this is that since BCI technology is intended to be an assistive tool, the most important factors in determining its benefits are the users' functional needs and actual experiences, not the opinions of their physicians. Furthermore, this approach acknowledges that people may experience disability in vastly different ways due to a myriad of personal and social factors, regardless of how similar their clinical assessments are. For instance, suppose that person A and B are both diagnosed with the same type of cerebral palsy, which results in a comparable degree of impairment in motor function and speech. Person A, who lives in a society where social interactions do not heavily depend on speech, or where people have no issue with her speech impediment, may only identify herself as a person with motor disability. Meanwhile, the society that person B lives in does not provide any accommodations for her difficulty in verbally expressing herself and even stigmatizes her for her unclear speech. Person B, thus, is likely to categorize her disability as both motor and communicative.

Therapeutic Misconception Questions

Given the recognized challenge of therapeutic misconception to informed consent, several methods have been proposed to capture its degree among study participants. Appelbaum

and colleagues' original project (Appelbaum, Roth, and Lidz 1982), and a fair amount of subsequent studies (e.g., Henderson et al. 2006; Abernethy et al. 2021; Grisso 2002; S. Y. H. Kim et al. 2009) have employed semi-structured interview to probe participants' understanding and expectation of their involvement in experimental studies. Although such a qualitative approach, perceived as the "gold standard" in measuring therapeutic misconception, can generate rich and detailed data, its lack of standardization renders it unsuitable for objective measurement and application in large-scale contexts (Appelbaum et al. 2012). Recognizing these problems, Appelbaum and colleagues have developed and introduced a validated method in 2012 to systematically quantify therapeutic misconception through a 10-item Likert-scale questionnaire[10] (Appelbaum et al. 2012). Such a standardized measurement is a crucial step in advancing our understanding of therapeutic misconception because it would enable researchers to compare findings across studies and populations more effectively. The questionnaire, therefore, will be built upon Appelbaum's measurement framework.

Thus far, research on therapeutic misconception has predominantly been conducted on individuals who are either current participants or prospective participants in specific clinical trials. The focus of existing literature, in other words, has been on individuals who have either undergone the informed consent process or are at least aware of the general terms and conditions of the trial they are considering. In these cases, measuring therapeutic misconception serves two direct purposes: evaluating the quality of the obtained consent, or serving as a preliminary assessment and allowing trial investigators to gauge the expectations of prospective participants and refine their plan accordingly. Beyond this project-specific approach, Appelbaum et al.

[10] To establish this tool, 220 participants from various clinical trials and trial phases across the US were recruited to complete a 28-item questionnaire and a follow-up semi-structured interview. The data collected from the questionnaire were then validated against the interview responses to ensure accuracy and reliability. The initial 28 items were then refined through factor analysis, resulting in the final true/false 10-item scale that corresponds to three main dimensions of therapeutic misconception, namely the mistaken beliefs about individualized treatment, purpose of the research project, and potential benefits (Appelbaum et al. 2012).

alluded that therapeutic misconception can also be measured more generically without being tied to any specific trials (Appelbaum et al. 2012, 4), as illustrated by the study on incarcerated individuals mentioned earlier (Christopher et al. 2016), as well as another by Kim and colleagues (S. Y. Kim et al. 2016).

Rather than measuring the presence of therapeutic misconception in a particular research setting, Kim et al.'s study shifts the focus to evaluating the *risk* of therapeutic misconception within a specific population – people with ALS. Although their research is intended as a critique of Appelbaum et al.'s measurement (Appelbaum et al. 2012) – a methodological debate unfortunately beyond the scope of this project – its alternative approach is worth considering. By expanding the pool of study subjects beyond those who have signed up for clinical research and studying people's understanding of clinical trials before they are directly exposed to any trial's recruitment and consent process, we might be able to determine whether misperception is shaped by informational gaps and structural issues that certain groups face, rather than the information provided within specific experiments.

Similar to the research by Kim and colleagues, this study will hence examine the *risk* of therapeutic misconception among individuals with the specific types of disabilities targeted by implantable BCI clinical trials. However, unlike Kim and colleagues who recruit participants in part via a clinical studies platform, thereby including in their pool of participation those who have expressed interests in partaking in clinical trials and are actively waiting for a suitable call, the current research will broaden the study sample to recruit participants who meet the relevant demographic criteria, regardless of whether they have considered joining any BCI clinical trials. Although this approach may initially seem unconventional, it addresses the concern for subject selection that Appelbaum raises in his commentary, titled "How not to test the prevalence of therapeutic misconception", which directly responds to Kim et al.'s study on ALS patients (Appelbaum 2016). Appelbaum flags that since more than 70% of their research participants

are recruited from a database of individuals who themselves sign up to be contacted for future clinical trials, there might be an overrepresentation of individuals with altruistic motivation who truly want to contribute to the advancement of science. While it remains an open question whether altruism characterizes those who volunteer for clinical trials, this research will mitigate Appelbaum's concern by recruiting participants outside of clinical trial databases.

Besides subject selection, Appelbaum also takes issue with Kim et al.'s limited measurement which assesses therapeutic misconception on solely one dimension regarding the purpose of the clinical trials. This restriction, Appelbaum argues, contributes to their finding of a lower-than-expected prevalence of therapeutic misconception among individuals with ALS. However, this particular critique does not apply to this research, as it will employ the scale devised by Appelbaum and colleagues themselves (Appelbaum et al. 2012) to capture all three dimensions of therapeutic misconception – the degree of treatment personalization, the chief purpose of a clinical study, and the benefits participants believe they will gain from the trials.

Another crucial concern more directly related to this current thesis is the use of hypothetical case to elicit participants' beliefs and expectations. To this, Appelbaum cautions that people's responses to imagined scenarios may not reflect their genuine reactions due to the lack of contextual influence. To minimize this concern for "ecological validity" (Appelbaum 2016), the hypothetical case used in this questionnaire will be closely informed by a systematic review of real-life BCI clinical trials (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024). By addressing these methodological concerns of Appelbaum with a more inclusive recruitment strategy, a comprehensive measurement that captures the three dimensions of therapeutic misconception and a hypothetical scenario that models after real-life BCI clinical trials, this study aspires to take on an undertaking that both builds upon and extends Appelbaum's original framework of defining and measuring therapeutic misperception. To provide a more rigorous

and representative analysis of therapeutic misconception, the use of an orienting hypothetical case is even a necessity in this research.

Before being introduced to the therapeutic misconception questions, participants are presented with a fictional story of a person named Alex who is considering the opportunity to sign up for a BCI clinical trial (see the full story in Appendix 3 or 4). In this survey, Alex's story serves a dual purpose. On the one hand, Alex's case is to some extent a standardized baseline for participants with varying experiences of disability. Given that how a disability necessitates assistance is highly dependent on individual circumstances, a study asking respondents to envision what a specific trial means to them might generate confusion as to whether the trial is at all relevant to their situation. By aligning Alex's specific disability with the respondent's previously identified category of disability (motor, sensory, or communicative) and establishing that Alex's disability significantly limits Alex's independence, the case helps clarify why the protagonist, as well as the respondent, would be a relevant candidate for BCI trials. Tailoring the case to reflect each respondent's type of disability also encourages them to draw on their own experience, thereby allowing the survey to capture the nuanced realities of specific forms of disability. Additionally, to reduce the likelihood of gender-related bias, the hypothetical protagonist is also presented with a gender-neutral name "Alex", and the story also has no gender-identifying details.

On the other hand, the hypothetical case is also a captivating story where respondents can get familiarize with implantable BCI technology and its clinical trials. This introduction ensures that all respondents, regardless of their prior knowledge or lack thereof of implantable BCI, start with a basic understanding of the technology. This includes BCI mechanism and intended purpose (part A in the hypothetical case, see Appendix 3 or 4 for the full text), typical trial tasks (B), time commitment (C) – key information that is usually provided in real-life calls for participants in BCI clinical trial – as well as some additional information that someone

interested in such trials might typically find when searching online (D). It is important to note that in reality, the technical details of each trial vary greatly and so does the volume of information that the participants receive before/ during their involvement in the experiment. To make the case as close to reality as possible, all the details of this made-up scenario are (average) values of all BCI trials identified up to the end of 2023 (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024).

To assess the prevalence of therapeutic misconception, this study adopts the measurement framework developed by Appelbaum and colleagues (Appelbaum et al. 2012), which consists of ten Likert-scale statements designed to capture therapeutic misconception along all three dimensions: expectation for the trial's individualization, purpose and benefits. Six of the ten items (two for each dimension) that are most suitable for the research will be utilized. Within their respective dimension, these six statements also provide higher accuracy for measuring therapeutic misconception[11]. Although the wording of the selected statements (Table 1) is slightly modified to align with the context of BCI trials, their overall structure remains largely unchanged to avoid invalidating the original measurement. Respondents are asked to rate on a five-point Likert scale the extent to which they believe that each statement is correct (1 = "Definitely not", 5 = "Definitely yes").

Table 1: Six statements used to measure the three dimensions of therapeutic misconception

Dimension	Statements
Individualization	(Individualization 1) When they design such BCI trials, researchers must ensure that each participant will receive the best possible treatment/solution for their individual needs, similar to the personalized care they would receive from their primary healthcare provider.

[11] In Appelbaum et al.'s study, this accuracy (more precisely, factor loadings) is defined in terms of the alignment between each person's therapeutic misconception level measured by the Likert-scale statements, and that measured by the in-depth interview (Appelbaum et al. 2012).

	(Individualization 2) In the BCI trials, researchers will always try to give each participant the device or setup that best addresses their unique needs.
Purpose	(Purpose 1) The trial's purpose is to provide the best solution (in this case – assistive device) available for Alex and other participants.
	(Purpose 2) The most important task for the researcher is to ensure that the trial will help its participants.
Benefits	(Benefits 1) The treatment/solution that Alex receives by participating in the trial is probably the best option for Alex.
	(Benefits 2) By taking part in a clinical trial, people like Alex will receive the best solution for their needs.

Exploratory Questions & Support Network Questions

Following Alex's case, the questionnaire proceeds with the four questions that will be used for the exploratory investigation. These questions ask whether the respondents think Alex should enroll in the trial, whether they would consider enrolling themselves, and what the reasons are behind each of those choices. The two first questions, measured on a scale of 1 (Definitely not) to 5 (Definitely yes), are not intended to measure manifestation of therapeutic misconception per se, but rather to serve as stepping stones for the justification questions that follow. They prompt respondents to think about the general appeals of the BCI clinical trial and articulate in writing the factors that either discourage or encourage them to participate in the trial. Considering that some respondents might have difficulties with writing responses, these are the only two questions in the questionnaire that are open-ended and optional.

Because these questions are directly linked to the hypothetical scenario, they appear before those addressing the thesis's second research question. To study the link between a disabled person's support network and therapeutic misconception, the last section of the questionnaire asks the respondents to assess the quality of support and care available to them. Survey participants are asked to indicate on a five-point scale ranging from "Definitely not" (1)

to “Definitely yes” (5) whether they feel sufficiently supported a/ by their local infrastructure, and b/ by their personal relationships.

CHAPTER 4: ANALYSIS AND DISCUSSION

Data collected from the questionnaire was then loaded into RStudio and NVivo, respectively for quantitative and qualitative analysis. Following an overview of the respondent's demographic characteristics, the second section of this chapter provides a descriptive analysis to evaluate the risk of therapeutic misconception among the pool of respondents (RQ1) and its connection with the quality of their support network (RQ2). Next, the qualitative analysis of the free text responses will explore the central themes that disabled people consider when deciding whether or not to join the BCI trial. The chapter then concludes with a comprehensive summary of principle findings, which will set the stage for the policy recommendations sketched out in the last chapter.

4.1. Data Overview

Over the span of one month, the survey received 36 completed submissions, 7 of which used the plain language version and none requested additional support to complete the survey. Out of this pool, 4 are invalid because the respondents are either underage (3 cases) or from a non-European country (1 from Kenya). This leaves the research with the final dataset comprising of 32 valid responses (n=32) from 18 countries[12]. The demographic characteristics of these respondents are presented in Appendix 5 and summarized in Table 2. Respondents are distributed across different age groups, with about 65% of the respondents aged 25-44 years old. The sample consists of mostly female (62.5%), and 75% reported having completed at

[12] Countries of the 32 valid survey participants: Austria (3 respondents), Belgium, Croatia, Denmark, Finland, France, Greece, Iceland, Italy (4), Lithuania (3), Malta, Netherlands (2), Portugal (2), Republic of Moldova, San Marino, Serbia (4), Slovakia (3), Switzerland.

least a Bachelors Degree. In terms of disability, the most popular type is motor (17), followed by sensory (11). There are 3 cases of having multiple types of disability.

Table 2: Demographic composition of all survey respondents (n=32), by levels of therapeutic misconception risk

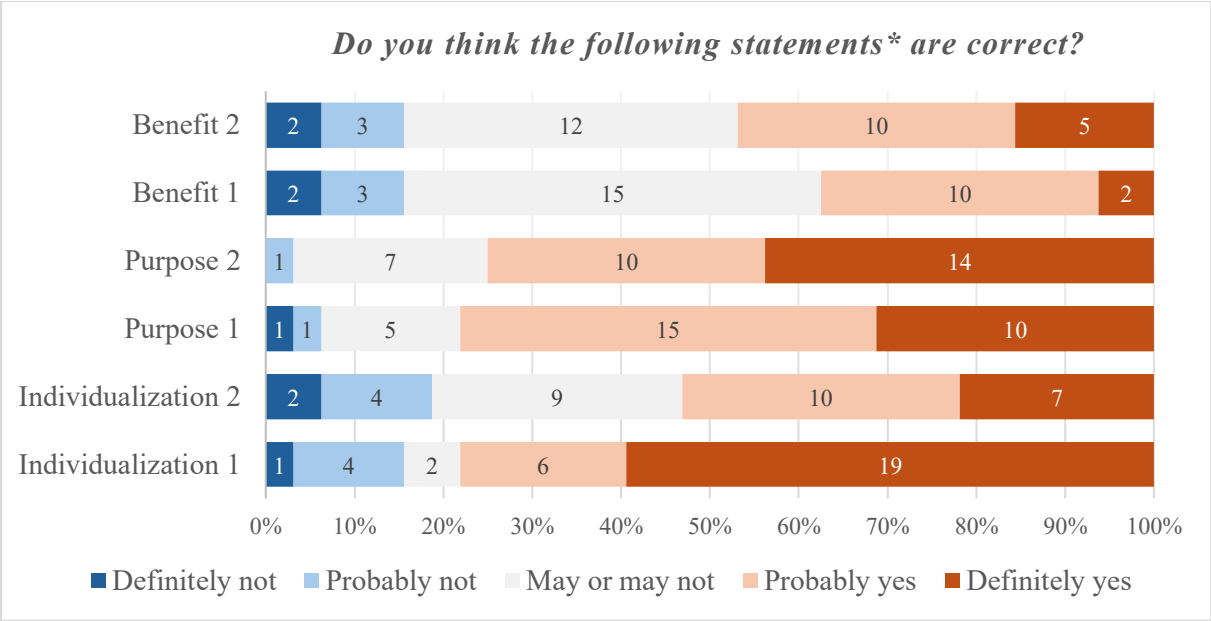
		Risk of therapeutic misconception		
	Total n=32 (%)	**Low** n=8	**Moderate** n=12	**High** n=11
Age group				
18-24 years old	6 (18.8)	1	4	1
25-34 years old	11 (34.4)	5	2	3
35-44 years old	10 (31.2)	2	5	3
55-64 years old	3 (9.4)	0	1	2
65+ years old	2 (6.2)	0	0	2
Gender				
Female	20 (62.5)	6	7	6
Male	11 (34.4)	1	5	5
Prefer not to say	1 (3.1)	1	0	0
Education level				
Some Secondary	2 (6.2)	0	1	1
Completed Secondary School	3 (9.4)	0	2	1
Some University but no degree	3 (9.4)	0	2	1
University Bachelors Degree	13 (40.6)	5	4	4
Graduate or professional degrees	11 (34.4)	3	3	4
Disability				
Sensory	11 (34.4)	4	3	4
Motor	17 (53.1)	2	7	7
Communicative	1 (3.1)	1	0	0
Sensory and Communicative	1 (3.1)	1	0	0
Sensory, Motor and Communicative	2 (6.2)	0	2	0

4.2. Sorting Therapeutic Misconception Risk: Low, Moderate and High

Regarding therapeutic misconception, the risks of misunderstanding the level of personalization and purpose of the BCI trial are noticeable among the respondents (Figure 1).

Nearly 80% of them (25/32) believed that the trial's design must answer the participants' personal needs (Individualization 1). About three-quarters of them held that the primary purpose of the trials (Purpose 1), as well as the trial investigators (Purpose 2), is to help the trial participants. Interestingly, despite such optimistic views, the majority of respondents remained neutral that taking part in the trial would benefit Alex and other participants (Benefits 1 and 2). Only 7 them expressed strong agreement with the statements highlighting the perceived benefits of participation in clinical trials.

Figure 1: Respondents' assessment of the six therapeutic misconception statements



(*) The six statements are presented in Table 1.

As the six statements related to Alex's case are all false misinterpretations of the trial's nature, and each is rated 1 (the statement is incorrect) to 5 (the statement is correct), respondent's total score for all statements will demonstrate their overall degree of therapeutic misconception. The higher the score, the greater the likelihood that they have misunderstood the level of personalization in the trial treatment, the trial's purpose, and/or its perceived benefits. The lowest total score indicating no risk of therapeutic misconception is 6 when the respondent consistently thinks that all the statements are false. On the contrary, an accumulative

point of 30 means a high risk of misjudging the nature of the clinical trial. Of the 32 responses, the average total point is 22, yet the points vary greatly between 12 and 29 with a standard deviation of 4.4. A full breakdown of each respondent's demographic details and therapeutic misconception point can be found in Appendix 5.

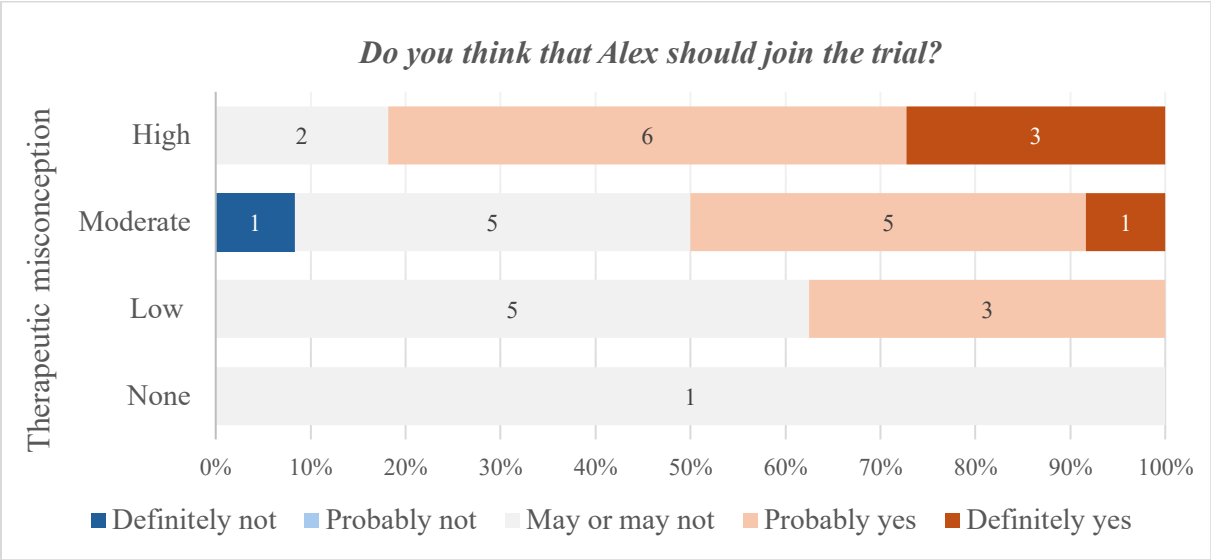
While this sum point approach is useful to compare a respondent's therapeutic misconception relative to others, a more nuanced and precise understanding of the phenomenon requires that the degree of misinterpretation be presented by the frequency of high-risk ratings (4 and 5) in a survey response. This is because technically, if a respondent gives a rating of 4 or 5 to any of the six statements related to Alex's case, it already indicates that they are misreading the nature of clinical trial in one of the three dimensions constituting therapeutic misconception. Simply adding up the points can obscure critical qualitative differences in the response with similar total point. For instance, two ranking combinations of 3-1-3-2-2-3 (in any order) and 1-1-1-4-3-4 would produce an identical aggregated score of 14, but only the second one demonstrates a clear misinterpretation of clinical trials whilst the first one seems to express a more neutral stance. Therefore, based on the number of statements rated 4 or 5 points, respondents can be categorized into three risk groups: low risk (those who give a score of 4 or 5 in one to two statements), moderate risk (three to four statements), or high risk (five to six statements). In the pool of 32 questionnaire respondents, 8 fall into the low-risk category, 12 are in the moderate group, 11 belong to the high-risk group. This classification of respondents into groups of therapeutic misconception risk levels will be the primary unit of analysis for the remainder of this study.

Except for one respondent who did not rate any statement higher than 3 points, 97% of the study sample (31/32) are at risk of having some degree of therapeutic misconceptions for BCI clinical trials. This high prevalence of misconception, consistent with the results frequently documented in existing studies of this phenomenon, has once again underscored that therapeutic

misconception is a pervasive issue in the context of experimental studies. Although the study's limited and unbalanced sample size has precluded a meaningful investigation of the correlations between therapeutic misconception levels and individual characteristics, there are a few discernible patterns that can help distinguish each risk group apart. Demographic-wise, it is suggestive that age and gender might have an effect on one's expectations for clinical trials – the relationships that have been confirmed by many previous empirical studies (e.g., Henderson et al. 2006; Dunn et al. 2006). The high-risk group, with about the same number of male and female respondents, contains considerably more senior adults than the other groups. Meanwhile, the low-risk category does not have anyone above the age of 44, and predominantly consists of women, with a sex ratio of six females to one male. The difference in terms of education is less clear – all the people expressing lowest level of misunderstanding in this sample have obtained at least a Bachelors Degree, while the education background of those with a higher degree of misconception is more dispersed (Table 2).

Besides these demographic differences, another distinction between these risk groups is that more individuals (9 out of 11) in the high-risk category were more confident that Alex should participate in the trial, whilst in the group of people who have a low-risk of therapeutic misconception, more than half of them neither agreed nor disagreed that this is a good idea for Alex and only three presumed that he probably should (Figure 2). A more detailed discussion of the justifications given for this question, presented in the qualitative analysis, would further elucidate how the groups diverge in their perceptions of the technology's benefits.

Figure 2: Support for Alex's participation in the hypothetical BCI trial, by levels of therapeutic misconception risk



4.3. Quality of Support Network and Therapeutic Misconception

When asked to evaluate the quality of support available to them, respondents clearly show that the quality of accommodations and care provided by their local environment are much worse than that offered by their personal relationships (Figure 3). Half of them disagreed that the statement *"*I feel sufficiently supported by the care and accommodation services available where I live*"* accurately reflects their situation. In stark contrast, 24 of them (75%) positively responded that they receive good support from family and friends.

When responses are sorted into groups of low/moderate/high therapeutic misconception risk, the rating pattern of each risk profile provides evidence against the initial assumption that those with a good support network would be less drawn to BCI trials and thereby less likely to hold inflated expectations for them. Instead, it is respondents with access to reliable support systems that have more serious therapeutic misconception. Although a larger share of the survey respondents (17) doubted the adequacy of support from their local community; among the minority of those who considered the support sufficient or somewhat sufficient, 9 out of 10

exhibited moderate to high risk of therapeutic misconception (Figure 4A). At the same time, the 12 respondents who strongly affirmed that they received decent support from people in their inner circles all demonstrate elevated risk levels (moderate to high) (Figure 4B). The results, thus, have uncovered a rather unexpected trend – that therapeutic misperception is disproportionately more common in people who, thanks to their robust support systems, would still be able to fare relatively well without the new capabilities unlocked by the BCI implants.

While it is beyond the limited scope of this thesis to explain the root cause behind this puzzle, the following exploratory analysis – designed to capture respondents' general thoughts on BCI trials – will offer some valuable insights into how the lived realities of people with disabilities may have shaped this result. As the written survey responses suggest, perceptions of BCI trials are shaped by a complex interplay of various factors, and not by the mere presence or absence of good support networks (at least when it is a stand-alone factor). Some people with reliable sources of support may still have high therapeutic misconception because, for instance, they are positive that new technologies such as BCI are necessary to facilitate independent living and are not too worried about the potential risks of the remained-to-be-tested technology. The thematic analysis, with the support of some illustrative excerpts, will help add more nuances to our understandings of how people with disabilities from various support backgrounds consider the values of participating in BCI clinical trials.

Figure 3: Ratings on the quality of support provided by local community and personal relationships

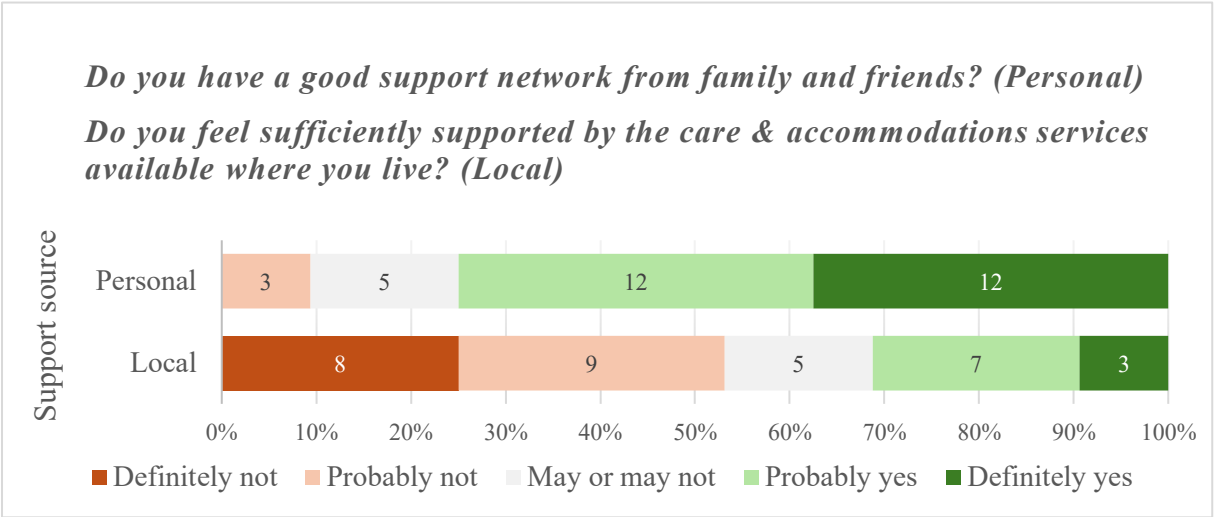
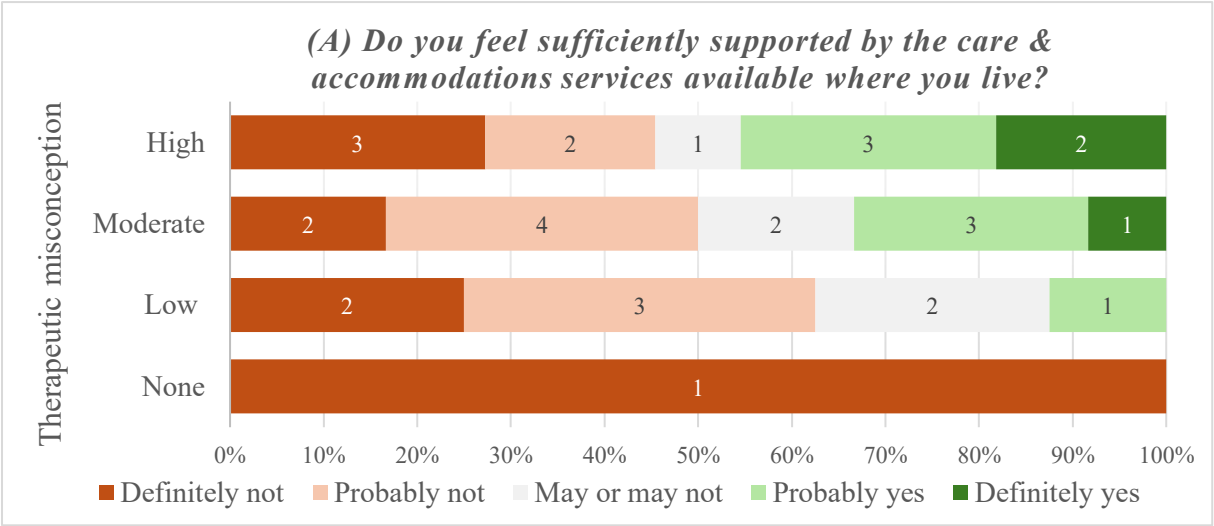
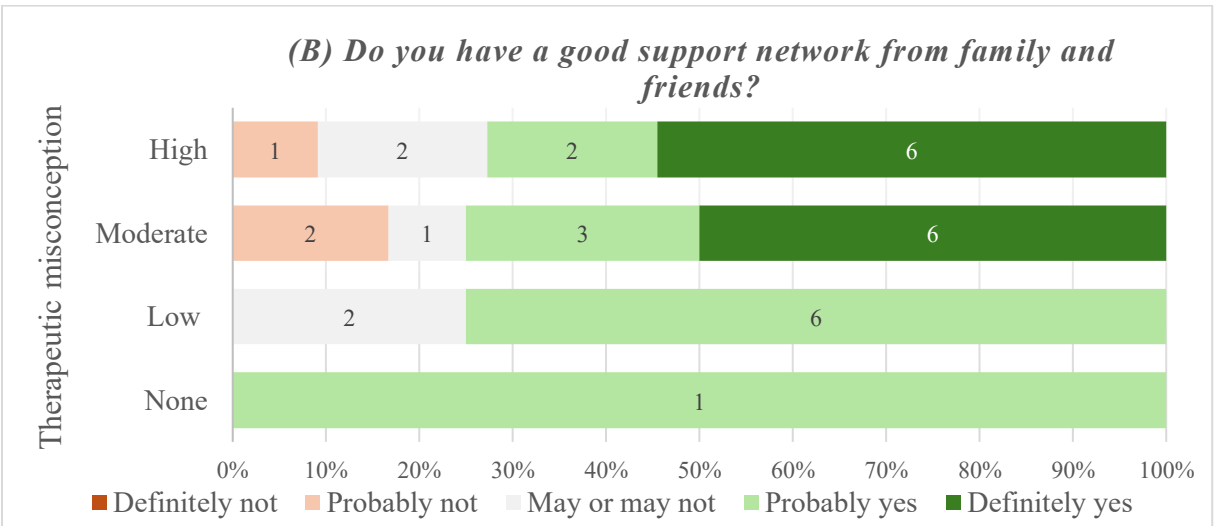


Figure 4: Ratings on the quality of support provided by (A) local community and (B) personal relationships, by levels of therapeutic misconception risk





4.4. An Exploratory Analysis of the Disabled's View on BCI Trials

To investigate what aspects stood out the most to survey respondents as they considered participation in BCI clinical trials, this section employs thematic analysis to inductively identify reoccurring themes in their justifications for why they think Alex and/or themselves should/ should not consider enrolling for the hypothetical trial[13]. Among the 32 respondents, 4 did not provide an explanation and are thus excluded from this thematic analysis (1 with moderate risk of therapeutic misconception, 3 with high risk). After a close reading of the responses, repeated terms and phrases are identified and, corresponding to their underlying messages, grouped into relevant thematic categories. Three most popular themes, all brought up by at least one-fourth of the survey participants, are summarized in Table 3.

Table 3: Predominant themes in respondents' justifications for why one should/ should not enroll for the hypothetical BCI trial (n=28)

Theme	**Sub-theme**	**Risk of therapeutic misconception** (None/ Low/ Moderate/ High)				**Respondents by support network quality***	
		N	**L**	**M**	**H**	**Poor**	**Good***
BCI's effect on independence (15)	Enabling (7)	-	1	1	5	#6, #30	**#3***, #**7**, **#10***, **#15**, **#32***
	Questionable (8)	1	3	4	-	#21	**#1**, #**2**, #**9**, **#26***, #**27**, **#29**, **#31**
Concerns (14)	Risk (11)	1	4	3	3	#4	**#2**, #**7**, #**9**, **#11**, **#12**, **#18**, **#19**, **#22**, #**23***, **#28***
	Invasiveness/ Surgery (9)	-	2	6	1	#4, #8	**#2**, **#11**, **#13**, #**18**, **#22**, **#28***, **#29**

[13] The analysis merges responses to the two questions whether Alex should sign up for the trial and whether the respondent themselves would sign up for the trial together because most of the written answers are only a few sentences long and most respondents provided similar justifications for both questions. The rating for Alex (whether Alex should join the trial, rated from 1 – "Definitely not" to 5 – "Definitely yes") was either the same as (12/32 cases) or marginally higher (19/32 cases) than the rating respondents gave for themselves. When the rating is higher, the average difference between the two ratings is 1.42. This suggests that respondents have applied largely similar reasoning frames to both Alex's case and their own case – i.e., almost all of them considered participation in the hypothetical BCI trial as equally valuable for Alex as for themselves, or only slightly less so, but rarely more for themselves than for Alex (only one case – Respondent 15).

Nature of decision (10)	Subjective (5)	-	1	3	1	#5, #24	**#1**, #**18, #29**
	Context-dependent (5)	1	3	1	-	#21	**#9**, #**19, #22, #31**

(*) Respondents considered well supported are respondents who rated "Probably yes" or "Definitely yes" to any of the two questions assessing the quality of their support network (the questions in Figure 3). Respondents well supported in both public and personal spheres are marked with an asterisk (*). Respondents with a high risk of therapeutic misconception are underlined.

Theme 1: Enabling an Independent Life?

In descending order, the most popularity theme is "BCI's effect on independence". It encompasses both the idea that the trial, as well as the BCI technology being tested, will likely improve the user's overall independence (sub-theme "Enabling") and those who doubt that is the case (sub-theme "Questionable"). In general, regardless of support quality, respondents are almost split over the two opposing camps. People with high risk of therapeutic misconception, people receiving solid support from both their local infrastructure and circle of acquaintances are both concentrated in the group that thinks highly of the independence-enabling potential of the tested technology. By contrast, among those skeptical that undergoing the trial will yield any positive effect on their independence, there is no high-risk profile and only one individual who obtains adequate assistance in both his/her public and private domains. Besides these compositional differences, the clarifications given by both sides have offered invaluable insights into how people with disabilities experience and interpret the concept of independence in many different ways.

For the positive group, expectations that the trial might warrant a more independent life for people with disabilities range from hopes of improved overall quality of life to willingness to seize any viable opportunity to become as independent as possible. Although no respondent in this "Enabling" camp explicitly alluded to how the availability of external accommodations

had informed their optimistic view, an intriguing answer by Respondent 32 signals that independence might be a capacity always worth seeking after, regardless of how sufficient accommodations are available. With a strong support system in the background, Respondent 32 – a person with ALS and a high risk of therapeutic misconception, expressed her interest to "take any chance" to minimize the need for external support, as she "would love to eat by [herself]" again. Beneath this seemingly straightforward statement are the complex and varied meanings that independence holds for people with disabilities.

In one potential reading, this motivation might stem from a person's deliberate consideration of their surroundings. Respondent 32 may wish to be less reliant on familial or institutional support – be it family members, personal assistants or any state-funded accommodations – not because such resources are not available or adequate to her needs, but because she does not want to be perceived as a burden to others. To many respondents in the same "Enabling" group, this psychological side-effect of BCI might potentially be a crucial component of what they had described as an "improvement in quality of life" for participants in BCI trials, as well as for future users of the technology (Respondent 10, 15). If such uneasiness of being reliant on others is a key driver behind therapeutic misconception, then we could expect that more respondents, especially those with a poor support network and those who have to rely more on familial care due to inadequate public support services, would show greater interest in experimental solutions such as BCI trials. However, as Figure 4A and 4B demonstrate, this is unlikely to be the case – it is not those least accommodated by their environment that have a higher risk of therapeutic misconception.

As much as this is a valid interpretation of what BCI trials can offer, an alternative, more radical perspective of independence also exists. On this view, independence may be valued in its own right and not just in terms of the possible outcomes it might produce (i.e., as a means to pursue other ends). To some disabled people, being able to perform their own routine can

hold intrinsic meaning that no form of accommodation and support, despite yielding the same outcome, can substitute. The desire to act on one's own, therefore, can persist even when support is sufficiently and adequately provided. That is to say, the motivation to seek for alternative means of support, including experimental studies such as BCI trials, does not necessarily originate from a need for accommodation, but more from a determination to reclaim agency and absolute control in one's life. Going back to the findings of the second research question, this more nuanced view of independence seems to be a promising explanation for why some people (as exemplified by the case of Respondent 32) whose support system is better than most still strive to improve their independence, and therefore are more likely to mistake experiment studies as an opportunity to achieve direct benefits.

Meanwhile, those who view the benefits of BCI as "questionable" tend to adopt a more holistic view of independence by suggesting that even when the received implant could help its users overcome their body limitations, that newfound independence is far from comprehensive. At large, their concerns can be captured under the broad stroke explanation given by Respondent 09, who is also the only respondent with no risk of therapeutic misconception: "[…] the concept of independence is very wide". Respondent 29 (with moderate risk) added: "Live with disability is a challenge and I don't think that putting a chip in [Alex's] brain is the best solution […] ". Instead of endorsing exploratory options such as BCI trials, many skeptics would either emphasize structural measures, such as providing personal assistance, to facilitate independent living (Respondent 2, 26, 27), or voice general concerns for the impacts of technology (Respondent 1 and 31). For those who prefer more sustainable solutions – those that are less invasive and can support a larger number of people with disabilities at once, while achieving the same support that BCI are designed to do – the attractiveness of BCI trials may understandably be reduced. Respondent 27 (a person with a moderate level of therapeutic misconception) noted:

> *I need to be sure the trial has the perspective of fulfilling my disability related need/ restoring sensory function. N.B.: Nowadays, such solutions do not necessarily need BCI implants/ surgery, as AI performs many such functions on a smartphone (e.g., describing/ interpreting pictures or sounds).*
>
> (Respondent 27)

Among the skeptics, two also flagged the problem with endorsing technological solutions. One low-risk respondent articulated distrust in the idea that techno-fixes are the best solutions (Respondent 31), while another, with moderate level of therapeutic misconception, observed that while the trial might help Alex to be more independent from others, it could simultaneously produce dependence on the technology (Respondent 1). Interestingly, of the total 28 written responses, only 3 (belonging to Respondents 1, 6, and 31) explicitly expressed some sentiments on technological approaches to disability. Expressing two opposing views towards technology, the owners of these responses also fall on opposing sides of the "Enabling" vs "Questionable" debate. In contrast to Respondents 1 and 31, Respondent 6 (with high risk of therapeutic misconception) demonstrated greater interest in the future of innovative technologies. As a seasoned tech expert who has extensive experience working with telecommunication tools, which he remarked have provided him with "great satisfaction", Respondent 6 was highly affirmative that BCI can improve users' independence.

Given the limited scope, whether such differing attitudes towards new technology and conceptualizations of independence contribute to the overall risk of therapeutic misconception remains an open question. However, the divided opinions among those well supported by their living environment, combined with a higher incidence of therapeutic misconception among individuals who view BCI as an enabling tool and new technology as highly promising accessibility solutions, suggest that such optimistic beliefs may have interacted with the quality of one's support network and influence their motivation to either endorse or condemn the BCI trials. Adding more depth to this perspective, the second most popular theme reveals that those

in the optimistic camp also tend to pay comparatively less attention to possible risks of BCI trials.

Theme 2: Salient Concerns

The second most salient theme reflects respondents' various "Concerns" for joining the trial or for implementing BCI technology. Their concerns range from general potential "Risk" to specific worries for the involved "Invasiveness/ Surgery" procedure. Notably, almost none of the 14 respondents raising concerns expressed a positive view on the possibility that the BCI trial would help improve one's independence. To the only exception – Respondent 7 (with high risk of therapeutic misconception), the fact that safety might be at risk did not completely deter her from the trial, but only lowered her confidence on whether or not Alex should sign up for the trial by one scale, to "Probably yes".

Apart from general potential risks, 9 respondents explicitly showed their apprehension for the involved surgical implantation. For most of them, the idea of interfering with the brain is deeply unsettling. As a respondent put it – "Opening the head or [putting] even a small needle and a foreign thing in someone's brain could hurt the brain or its functioning" (Respondent 28). To some extent, this reluctance to undergo head surgery also touches upon an ontological question concerning human nature. Implying that introducing an unnatural addition to the body could compromise her sense of self and expressing strong opposition against the idea of participating in the hypothetical BCI trial, Respondent 13 explains:

> *[Alex should "definitely not" sign up for the BCI trial because of] the fact that he will be needing an operation. I feel like [Alex] will become like a robot.*
>
> *I do not trust and I am not willing to have a chip inserted. I wanted to stay as I am… a human.*
>
> (Respondent 13)

Such anxieties for the unknown risks, for the surgery, and for the potential of blurring the line between human and machine, are widely shared across the general public (El-Osta et al. 2025; Almanna et al. 2025; Schmid et al. 2021). Corresponding with Respondent 13's worry, a survey done by Pew Research Center in 2021 has shown that 63% of American adults think that the use of brain chips is equated with "meddling with nature"[14] (Tyson 2022). While these concerns, often dampening enthusiasm for BCI, are not limited to people with disabilities, disability can significantly complicate how such risks are experienced and navigated. Before even considering disability-related factors, there is already a staggering number of up to 841 types of risks that can emerge throughout the life cycle of a BCI system, from development to deactivation (King, Read, and Salmon 2025). For disabled users, these stakes can be heightened by their underlying conditions or existing unjust socio-political arrangements. For instance, Respondent 22 remarked: "Because of my impairment, surgeries might be risky for me". Hence, even though the main concerns raised by the survey respondents are not disability-specific issues in the narrow sense (i.e., issues that only people living with disability face), it is important to note that the presence of disability can introduce multiple layers of complexity. To minimize this problem, it is crucial to listen to disabled people's perspectives and, above all, to respect their complete autonomy in deciding whether to adopt BCI interventions – another point highlighted by most survey respondents.

Theme 3: (Re)claiming the Agency in Decision-making

The last theme – "Nature of decision" – covers the third most salient topic in the study sample: a widely shared belief that decision to participate in BCI trials should be entirely up to each individual ("Subjective" category) or is driven by specific contexts ("Context-dependent"

[14] In contrast with 35% who contended that BCI is only an extension of other existing tools we have used to supplement human capacities (Tyson 2022).

category). In general, most people who referenced this theme in their response displayed only a mild to moderate degree of therapeutic misconception, and the only one with pronounced risk also asserted that Alex should have "absolute freedom to decide what is best from his point of view" (Respondent 24). Once again, people who questioned the prospect of enhancing independence (i.e., those who voiced skepticism towards the trial) have shown clearer hesitation, as they constitute half of the people who said that the decision to participate in the clinical trial if not determined by Alex, could only be made if they knew more about Alex's circumstances (Respondent 1, 9, 21, 29, 31). The fact that some level of therapeutic misconception exists among all the respondents – including a person with a high total point of 28 such as Respondent 24 – suggests that even without a clear distinction between research settings and personalized therapy, there is still a widespread commitment to ensuring that the decision is ultimately up to each individual with disabilities. The salience of this theme can be interpreted in two complementary ways, corresponding with the two sub-themes.

On the one hand, this emphasis on the ability to take ownership of decisions may be a reflection of a long history of marginalization and structural injustice that the disability community experiences. Although disability rights, thanks to decades of disability activism, are more widely recognized and respected nowadays, this reminder that people with disability should be able to dictate the course of their own lives is not at all outdated. Paternalistic views on disability, intentional or not, linger still even in the most liberal and developed countries. For instance, a recent public survey conducted on more than 800 adults in the UK found that whilst nearly 95% of respondents had never used a BCI application, a considerable percentage of them endorsed BCI applications for people with disabilities. Half of them even agreed that it is morally wrong for healthy individuals to use invasive BCI, while 65% believed that the use of invasive BCI should be restricted to people with physical and/or cognitive disabilities (El-Osta et al. 2025). In the same light, a 2023 experimental study has shown that when the public

learns that a disabled person rejects the use of BCI, they tend to direct blame and anger towards that person (Sample et al. 2023). Responding to such situations, Respondent 5 asserted – "I think that the world would be better if people like Alex could get the assistance they needed without other people who have never experienced a disability dictating what is best for Alex."

On the other hand, the sub-theme "Context-dependent" further elucidates the importance of letting disabled individuals decide on their own case by hinting at the diversity of the disability experience itself. In conjunction with the second theme "Concerns", this emergent theme reiterates that disabled people – the real experts in the experience and challenges associated with disabilities – should not only be able to exercise independent judgment over their involvement in clinical trials, but must also be consulted in the development of innovations directly targeting them. Despite articulating their ideas in different ways, the five respondents whose views are represented by this sub-category stressed that since one's experience with disability rests on many circumstantial factors unique to his or her life, no one – even those having the same type of bodily impairments – can presume to make that decision on whether to enroll in a BCI trial on behalf of another. Neatly tying together the exploratory investigation, this rationale is perfectly captured in the words of Respondent 31:

> *[Participating in the BCI trial] may be the best present option for them, but not necessarily all people with a similar condition. It depends on their own negotiations with their life circumstances and options available.*
>
> (Respondent 31)

4.5. Summary of Key Findings and Discussion

The survey, which gathers insights from 32 adults with diverse needs living across Europe, has revealed an alarming risk of therapeutic misconception among people with

disabilities (H1 is supported). When introduced to a hypothetical implant BCI trial, almost all (31/32) of the respondents failed to distinguish clinical trials from ordinary medical treatment in at least one of three aspects: the level of personalization received, the trial's primary purpose and the participant's overall benefits. Over 70% misunderstood that the trial is designed to address their individual needs (Individualization 1, Figure 1), and that its primary purpose is to help the involved participants and to provide them with the latest adaptive device (Purpose 1, Figure 1). About one-third (11/32) are especially at high risk of compromising their consent should they consider partaking in a real-life trial, since they misjudged all three respects that constitute therapeutic misconception.

Since implanted BCI enables users to directly operate a range of external assistive devices without using physical force, one of the main selling points of BCI trials lies in the technology's promise to afford disabled users more freedom from external help. Yet, there is no evidence that people with disabilities who live in a poorly supported environment would be more drawn to the opportunity of trying out such a transformative device in clinical settings (H2 is rejected). Quite the contrary, the data has shown that it is people who have access to adequate local and relational support that have a higher degree of therapeutic misconception. By zooming out and offer a more complete view of how people with disabilities perceive BCI clinical trials, the exploratory investigation unveils some factors that may have contributed to this counterintuitive result.

In justifying their interest, or lack of interest, in enrolling for BCI clinical trials, there are three topics most frequently discussed by the survey respondents: the independence-enabling effect of BCI trials, the procedure's safety, and the right of people with disabilities to make autonomous decisions on BCI trial participation and usage. As for the first theme, the respondents were almost equally divided over the potential of BCI on facilitating an independent life. Most of the respondents – including many who receive sufficient

accommodation from their local environment and personal network – who expressed optimism about the new technology's potential to enhance self-sufficiency and quality of life for people with disabilities demonstrated a high risk of therapeutic misconception. Whilst the average risk level is relatively lower for those who were skeptical of the technology's impact on independence. The skeptics also placed greater emphasis on structural measures alternative to BCI that can accommodate a broader range of individuals with disability. On top of that, they were more anxious about the trial's potential risks and invasive procedure. Even though the concerns they voiced do not distinctly differ from those of non-disabled people, these problems may be exacerbated by existing disability-related challenges and place them at a disproportionately greater risk than the general population. Given that disability experience varies greatly among individuals, just as the third theme underscores, many respondents have stressed that the decision on whether to enroll in a BCI trial or to adopt other assistive device should ultimately remain an autonomous choice of the disabled person.

All in all, the responses have shown that endorsement of BCI trials is not merely a question of accessibility needs. To many, it is nothing short of a question of philosophical and political beliefs – from whether independence should be valued intrinsically or instrumentally; whether one must seek to dismantle ableist social arrangements instead of supporting disability-deleting solutions such as BCI; to whether the voice of persons with disability is genuinely respected in the process. The answers to these crucial questions can only be found via direct dialogues and engagement with people with disabilities themselves, just as this study has done. As a result, a consent procedure requesting voluntary participation and outlining the involved procedures is only the first step in protecting participants' rightful interests. Instead, it should also seek to understand what participants expect to achieve by being involved in a project that may not provide them with direct benefits. It is true that the researchers' duty is not to guarantee all participants' expectations are met, or that participants do not have any expectation at all –

in many cases, a positive attitude toward the tested treatment may even beneficial. However, it is important that participants' overall expectations are not misled or overly inflated, such that they cannot give due consideration to the stakes involved, or worse, set themselves up for disappointment as they gradually come to the realization that at the end of the day, the trial is not meant to serve them per se. Fending off therapeutic misconception in experiments of new technology, especially when individuals with disabilities or other vulnerable populations are involved, is therefore necessary to uphold the research's ethical integrity and to guarantee that the technology being developed truly serves its intended beneficiaries.

CHAPTER 5: CONCLUSION

5.1. Some Policy Recommendations

In light of the above research findings and reflections, there is little doubt that the consent procedure for research involving vulnerable groups needs to be strengthened to effectively protect its participants' interests. This section will sketch out some policy recommendations to specifically tackle the problem of therapeutic misconception in clinical trials. As this is a complex issue, addressing it requires active cooperation between (prospective) trial participants and experimental researchers, as well as more accountability from other social actors beyond the trial context – such as the media – that can influence perceptions of BCI studies.

To begin with, the pervasive presence of therapeutic misconception among survey participants despite their divided view over the independence-improving benefit of BCI suggests that the misunderstanding may even stem from a general lack of clarity on the nature of experimental interventions and less from the technology itself. In that regard, consent procedure in clinical trials of BCI, or other new technologies targeting people with disabilities, should allow more space for participants to share their perspective, as well as the considerations that motivate them to join the trial. Most importantly, researchers need to recognize that individual's expectations are heavily influenced by the social environment in which they live, and especially for members of vulnerable groups – by their experience with societal biases and systemic exclusion.

In addition, the fact that such a sample of highly educated, English-speaking people still failed to distinguish experimental studies from clinical treatment indicates that an extensive informational procedure alone might not suffice. Informed consent thus should not be treated

as a one-time procedural formality, but rather as an ongoing, interactive process and, if possible, consists of various check-ins at different stages of the study duration. These sessions would not only allow participants to revisit and revise their decisions as the study unfolds, but also enable trial investigators to identify early on any misalignment between their vision of the trial's purpose and that of the participants. Since the consent procedure is often limited in time and space, it would be particularly useful if trial participants could have access to additional, reliable resources to learn more about previous studies of the same kind. In on-human clinical trials, it is therefore essential to promote research transparency and more responsible media coverage, especially in the case of BCI trials – where publications of prior trials' results are often limited whilst the technology's direct interaction with the human brain has attracted intense media attention.

5.2. Limitations and Venues for Future Research

While the present study has identified some areas in which the consent procedure of implant BCI trials could improve on, the generalizability of its findings can be hindered by a few research limitations concerning the limited study sample, the social approach of defining disability, and the shortcomings of using survey to collect data on such a complex topic. This section reflects on these shortcomings and outlines some fertile venues for future research.

First and foremost, the analysis is drawn on a small and unbalanced sample. While more than 170 organizations and associations of people with disabilities across Europe were contacted, the survey was accessed by 86 people, and only 36 of them ended up finishing and submitting it (including the 4 invalid responses). Considering that this is an online survey that requires a certain level of English proficiency, those without access to the Internet and/or knowledge of English language, might be excluded by default. On top of that, this small cohort

consists mostly of female, highly educated individuals coming from diverse social, political backgrounds. A more comprehensive and representative sample would allow for a more robust analysis of therapeutic misconception and its relationship with other factors – ranging from, for instance, demographic and behavioral characteristics to political ideologies.

Second, the method of letting the respondents decide whether they identify themselves as a person with disability instead of relying on concrete medical diagnoses is both a strength and a weakness of this study. On the one hand, this inclusive approach has enabled richer insights into the diverse experience of life with disability, thereby serving the research's aim of bringing the expertise of people with disabilities to the forefront of research ethics. Yet, on the other hand, it also casts such a wide net that many of the recorded respondents would not be considered eligible candidates for real-life BCI trials. By operating mainly on the social model of disability, parts of the survey which collect data on the disability's medical cause and its curability were not discussed in the analysis[15]. Subsequent studies may explore the impacts of such medical factors on therapeutic misconception and study the phenomenon in a more conventional way by focusing on people who are considering or participating in BCI trials. Research following this direction can benefit from the substantive literature that examines the extent to which would-be participants in a specific trial fully understand what they sign up for. Alternatively, a questionnaire using hypothetical scenarios similar to the one used in this study can be conducted on non-disabled people to delineate, for instance, the difference between those who approach this as a tool to participate in society on a more equal footing as others, and those who approach this as an exciting experiment to expand the limits of human capacity. Similarly, another promising area of inquiry concerns the risk of therapeutic misconception among clinical trial researchers themselves, who may instill false impressions on research participants when they exhibit excessive enthusiasm for the BCI project they are working on. Investigating

[15] Due to the limited scope, data on respondent's past experience with experimental studies was also not utilized.

therapeutic misconception from the vantage point of other stakeholders and contrasting these views with those of people with disabilities could provide a more dynamic and complete understanding of the phenomenon.

Last but not least, while the questionnaire is convenient to collect data from a group of diverse accessibility needs, it provides only a partial snapshot of the respondents' perspectives. Follow-up in-depth interviews would have facilitated a more nuanced understanding of the respondents' expectations for BCI trials. This will give survey participants the opportunity to reflect on their answers and ask for any clarifications if necessary – which is particularly important for those who are unfamiliar with BCI technology. Returning to the "gold standard" to measure therapeutic misconception will also allow researchers to iron out contradictions such as why some respondents, despite rightly recognizing the correct nature of clinical trials, still exhibited some degree of therapeutic misconception. For instance, a respondent with moderate risk noted: "[…] from what I've understood the trial will not be adjusted to his [Alex] specific needs. (It is a trial, so probably it is some general "beta" version for all, adjusted only on general level?)" (Respondent 3). Giving respondents the opportunity to elaborate on their answers will therefore ensure the internal consistency of their response and improve the overall validity of the collected data.

5.3. Final Remarks

From the historical exclusion of people with disabilities to their encouraged participation in the development of new scientific knowledge, from the early emphasis on voluntary consent to a more nuanced concept of informed consent that requires meaningful engagement with the community of research *participants* (and not the research *subjects*) – it has been a long journey for both research ethics and people with disabilities. By studying the

risk of therapeutic misconception in a hypothetical implantable BCI trial, the thesis aims to highlight how the development of a new technology – despite directly involving the socially vulnerable population it intends to benefit – can still wrong them if it fails to take into consideration their distinct lived experience. Evidenced by the heightened risk of having inflated expectations for BCI clinical trials among the 32 surveyed disabled individuals, even among those with a good support system in place, ethical research protocols in general and the consent procedure in on-human experiments of new technology specifically need to be reformed to better safeguard the interests of research participants. Furthermore, as the complementary exploratory analysis demonstrates, the standpoint knowledge of the disability community is as valuable as it is diverse. Beyond the need to restore bodily functions, there is a range of other factors that shape how individuals perceive the charm of participating in BCI clinical trials. As such, the consent procedure should be a more dynamic process in which each participant's voluntary participation is meaningfully situated within the context of their everyday life and experiences outside the research's settings. Although much remains to be studied to evaluate the significance of its findings, the thesis – one of the first empirical studies that measure people with disability's views on BCI trials – has attempted to make a meaningful contribution to how the disability perspective can inform and refine research ethics, especially in the field of emerging technologies.

REFERENCES

Abernethy, Eli R., Gavin P. Campbell, Rachel S. Hianik, Mary Catherine Thomson, Shannon M. Blee, Hannah C. Sibold, Margie D. Dixon, Jeffrey M. Switchenko, and Rebecca D. Pentz. 2021. "Reassessing the Measurement and Presence of Therapeutic Misconception in a Phase 1 Setting." *Cancer* 127 (20): 3794–3800. https://doi.org/10.1002/cncr.33746.

Almanna, Mohammed A., Lior M. Elkaim, Mohammed A. Alvi, Jordan J. Levett, Ben Li, Muhammad Mamdani, Mohammed Al-Omran, and Naif M. Alotaibi. 2025. "Public Perception of the Brain-Computer Interface: Insights from a Decade of Data on X." *JMIR Formative Research*, January. https://doi.org/10.2196/60859.

Anderson, Elizabeth. 2024. "Feminist Epistemology and Philosophy of Science." In *The Stanford Encyclopedia of Philosophy*, edited by Edward N. Zalta and Uri Nodelman, Fall 2024. Metaphysics Research Lab, Stanford University. https://plato.stanford.edu/archives/fall2024/entries/feminism-epistemology/.

Appelbaum, Paul S. 2016. "How Not to Test the Prevalence of Therapeutic Misconception." *Journal of Medical Ethics* 42 (8): 519–20. https://doi.org/10.1136/medethics-2016-103466.

Appelbaum, Paul S, Milena Anatchkova, Karen Albert, Laura B Dunn, and Charles W Lidz. 2012. "Therapeutic Misconception in Research Subjects: Development and Validation of a Measure." *Clinical Trials* 9 (6): 748–61. https://doi.org/10.1177/1740774512456455.

Appelbaum, Paul S., Loren H. Roth, and Charles Lidz. 1982. "The Therapeutic Misconception: Informed Consent in Psychiatric Research." *International Journal of Law and Psychiatry* 5 (3): 319–29. https://doi.org/10.1016/0160-2527(82)90026-7.

Appelbaum, Paul S., Loren H. Roth, Charles W. Lidz, Paul Benson, and William Winslade. 1987. "False Hopes and Best Data: Consent to Research and the Therapeutic Misconception." *The Hastings Center Report* 17 (2): 20–24. https://doi.org/10.2307/3562038.

Beck, Savannah, Yuliya Liberman, and Veljko Dubljević. 2024. "Media Representation of the Ethical Issues Pertaining to Brain–Computer Interface (BCI) Technology." *Brain Sciences* 14 (12): 1255. https://doi.org/10.3390/brainsci14121255.

Benjamin, Ruha. 2019. *Race After Technology: Abolitionist Tools for the New Jim Code*. Wiley.

Bidleman, Cricket X. 2021. "Opinion | Technology Can't Solve the Problems Ableism Creates." *The Standford Daily*, October 26, 2021, sec. Opinions. https://stanforddaily.com/2021/10/26/technology-cant-solve-the-problems-ableism-creates/.

Bracken-Roche, Dearbhail, Emily Bell, Mary Ellen Macdonald, and Eric Racine. 2017. "The Concept of 'Vulnerability' in Research Ethics: An in-Depth Analysis of Policies and Guidelines." *Health Research Policy and Systems* 15 (1): 8. https://doi.org/10.1186/s12961-016-0164-6.

Burwell, Sasha, Matthew Sample, and Eric Racine. 2017. "Ethical Aspects of Brain Computer Interfaces: A Scoping Review." *BMC Medical Ethics* 18 (1): 60. https://doi.org/10.1186/s12910-017-0220-y.

Charuvastra, A, and S R Marder. 2008. "Unconscious Emotional Reasoning and the Therapeutic Misconception." *Journal of Medical Ethics* 34 (3): 193–97. https://doi.org/10.1136/jme.2006.018960.

Christopher, Paul P., Michael D. Stein, Sandra A. Springer, Josiah D. Rich, Jennifer E. Johnson, and Charles W. Lidz. 2016. "An Exploratory Study of Therapeutic Misconception among Incarcerated Clinical Trial Participants." *AJOB Empirical Bioethics* 7 (1): 24–30. https://doi.org/10.1080/23294515.2015.1058303.

Churchill, Larry R., Myra L. Collins, Nancy M. P. King, Stephen G. Pemberton, and Keith A. Wailoo. 1998. "Genetic Research as Therapy: Implications of 'Gene Therapy' for Informed Consent." *Journal of Law, Medicine and Ethics* 26 (1): 38–47. https://doi.org/10.1111/j.1748-720X.1998.tb01904.x.

Crasnow, Sharon. 2014. "Feminist Standpoint Theory." In *Philosophy of Social Science: A New Introduction*, edited by Nancy Cartwright and Eleonora Montuschi, 145–61. Oxford University Press.

Dhai, A. 2014. "The Research Ethics Evolution: From Nuremberg to Helsinki." *SAMJ: South African Medical Journal* 104 (3): 178–80.

Dunn, Laura B., Barton W. Palmer, Monique Keehan, Dilip V. Jeste, and Paul S. Appelbaum. 2006. "Assessment of Therapeutic Misconception in Older Schizophrenia Patients with a Brief Instrument." *The American Journal of Psychiatry* 163 (3): 500–506. https://doi.org/10.1176/appi.ajp.163.3.500.

Durand-Zaleski, I. S., C. Alberti, P. Durieux, X. Duval, S. Gottot, Ph Ravaud, S. Gainotti, C. Vincent-Genod, D. Moreau, and P. Amiel. 2008. "Informed Consent in Clinical Research in France: Assessment and Factors Associated with Therapeutic Misconception." *Journal of Medical Ethics* 34 (9): e16–e16. https://doi.org/10.1136/jme.2007.023473.

El-Osta, Austen, Mahmoud Al Ammouri, Shujhat Khan, Sami Altalib, Manisha Karki, Eva Riboli-Sasco, and Azeem Majeed. 2025. "Community Perspectives Regarding Brain-Computer Interfaces: A Cross-Sectional Study of Community-Dwelling Adults in the UK." *PLOS Digital Health* 4 (2): e0000524. https://doi.org/10.1371/journal.pdig.0000524.

European Medicines Agency. 2009. "Compassionate Use." European Medicines Agency (EMA). December 31, 2009. https://www.ema.europa.eu/en/human-regulatory-overview/research-development/compassionate-use.

Fisher, Carl Erik, Laura B. Dunn, Paul P. Christopher, Paul E. Holtzheimer, Yan Leykin, Helen S. Mayberg, Sarah H. Lisanby, and Paul S. Appelbaum. 2012. "The Ethics of Research on Deep Brain Stimulation for Depression: Decisional Capacity and Therapeutic Misconception." *Annals of the New York Academy of Sciences* 1265 (1): 69–79. https://doi.org/10.1111/j.1749-6632.2012.06596.x.

Frauenberger, Christopher. 2015. "Disability and Technology: A Critical Realist Perspective." In *Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility - ASSETS '15*, 89–96. Lisbon, Portugal: ACM Press. https://doi.org/10.1145/2700648.2809851.

Friesen, Phoebe, Luke Gelinas, Aaron Kirby, David H Strauss, and Barbara E Bierer. 2023. "IRBs and The Protection-Inclusion Dilemma: Finding a Balance." *The American Journal of Bioethics : AJOB* 23 (6): 75–88. https://doi.org/10.1080/15265161.2022.2063434.

Glazko, Kate, Yusuf Mohammed, Ben Kosa, Venkatesh Potluri, and Jennifer Mankoff. 2024. "Identifying and Improving Disability Bias in GPT-Based Resume Screening." In *The 2024 ACM Conference on Fairness, Accountability, and Transparency*, 687–700. Rio de Janeiro Brazil: ACM. https://doi.org/10.1145/3630106.3658933.

Gordon, Bruce G. 2020. "Vulnerability in Research: Basic Ethical Concepts and General Approach to Review." *The Ochsner Journal* 20 (1): 34–38. https://doi.org/10.31486/toj.19.0079.

Gordon, Emma C., and Anil K. Seth. 2024. "Ethical Considerations for the Use of Brain–Computer Interfaces for Cognitive Enhancement." *PLOS Biology* 22 (10): e3002899. https://doi.org/10.1371/journal.pbio.3002899.

Graceshalini, T., S. Rathnamala, and M. Prabhanantha Kumar. 2023. "A Review of Innovation to Human Augmentation in Brain-Machine Interface – Potential, Limitation, and Incorporation of AI." In *Brain-Computer Interface*, 101–25. John Wiley & Sons, Ltd. https://doi.org/10.1002/9781119857655.ch5.

Grisso, Thomas. 2002. "Method for a Study of Therapeutic Misconception." Working paper 1. University of Massachusetts Medical School, The Center for Mental Health Services Research.

Haraway, Donna. 1988. "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist Studies* 14 (3): 575–99. https://doi.org/10.2307/3178066.

Harding, Sandra. 2003. "How Standpoint Methodology Informs Philosophy of Social Science." In *The Blackwell Guide to the Philosophy of the Social Sciences*, edited by Stephen P. Turner and Paul A. Roth, 1st ed., 291–310. Wiley. https://doi.org/10.1002/9780470756485.ch12.

Hasler, Frances. 2003. "Philosophy of Independent Living." Independent Living Institute. 2003.

Henderson, Gail E., Michele M. Easter, Catherine Zimmer, Nancy M. P. King, Arlene M. Davis, Barbra Bluestone Rothschild, Larry R. Churchill, Benjamin S. Wilfond, and Daniel K. Nelson. 2006. "Therapeutic Misconception in Early Phase Gene Transfer Trials." *Social Science & Medicine* 62 (1): 239–53. https://doi.org/10.1016/j.socscimed.2005.05.022.

Hosseini, Negar, and Praveen Kumar. 2020. "Gaps in Neuroethics in Relation to Brain Computer Interfaces: Systematic Literature Review." In *Human-Computer Interaction. Human Values and Quality of Life*, edited by Masaaki Kurosu, 448–74. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-030-49065-2_32.

Jansen, Lynn A. 2020. "Informed Consent, Therapeutic Misconception, and Unrealistic Optimism." *Perspectives in Biology and Medicine* 63 (2): 359–73. https://doi.org/10.1353/pbm.2020.0024.

Kim, Scott Y. H., Lauren Schrock, Renee M. Wilson, Samuel A. Frank, Robert G. Holloway, Karl Kieburtz, and Raymond G. De Vries. 2009. "An Approach to Evaluating Therapeutic Misconception." *IRB* 31 (5): 7–14.

Kim, Scott Yh, Renee Wilson, Raymond De Vries, Kerry A Ryan, Robert G Holloway, and Karl Kieburtz. 2016. "Are Patients with Amyotrophic Lateral Sclerosis at Risk of a Therapeutic Misconception?" *Journal of Medical Ethics* 42 (8): 514–18. https://doi.org/10.1136/medethics-2015-103319.

Kimmelman, Jonathan. 2007. "The Therapeutic Misconception at 25: Treatment, Research, and Confusion." *Hastings Center Report* 37 (6): 36–42. https://doi.org/10.1353/hcr.2007.0092.

King, Brandon J., Gemma J. M. Read, and Paul M. Salmon. 2025. "Prospectively Identifying Risks and Controls for Advanced Brain-Computer Interfaces: A Networked Hazard Analysis and Risk Management System (Net-HARMS) Approach." *Applied Ergonomics* 122 (January):104382. https://doi.org/10.1016/j.apergo.2024.104382.

Klein, Eran. 2016. "Informed Consent in Implantable BCI Research: Identifying Risks and Exploring Meaning." *Science and Engineering Ethics* 22 (5): 1299–1317. https://doi.org/10.1007/s11948-015-9712-7.

Leykin, Yan, Paul P. Christopher, Paul E. Holtzheimer, Paul S. Appelbaum, Helen S. Mayberg, Sarah H. Lisanby, and Laura B. Dunn. 2011. "Participants' Perceptions of Deep Brain

Stimulation Research for Treatment-Resistant Depression: Risks, Benefits, and Therapeutic Misconception." *AJOB Primary Research* 2 (4): 33–41. https://doi.org/10.1080/21507716.2011.627579.

Lidz, Charles W., Karen Albert, Paul Appelbaum, Laura B. Dunn, Eve Overton, and Ekaterina Pivovarova. 2015. "Why Is Therapeutic Misconception so Prevalent?" *Cambridge Quarterly of Healthcare Ethics: CQ: The International Journal of Healthcare Ethics Committees* 24 (2): 231–41. https://doi.org/10.1017/S096318011400053X.

Lidz, Charles W., and Paul S. Appelbaum. 2002. "The Therapeutic Misconception: Problems and Solutions." *Medical Care* 40 (9): V55–63.

Lidz, Charles W, Paul S Appelbaum, Thomas Grisso, and Michelle Renaud. 2004. "Therapeutic Misconception and the Appreciation of Risks in Clinical Trials." *Social Science & Medicine* 58 (9): 1689–97. https://doi.org/10.1016/S0277-9536(03)00338-1.

Liu, Lili, Christine Daum, Antonio Miguel Cruz, Noelannah Neubauer, Hector Perez, and Adriana Ríos Rincón. 2022. "Ageing, Technology, and Health: Advancing the Concepts of Autonomy and Independence." *Healthcare Management Forum* 35 (5): 296–300. https://doi.org/10.1177/08404704221110734.

Mor, Sagit. 2018. "Nothing about Us without Us: A Disability Challenge to Bioethics." In *Bioethics and Biopolitics in Israel: Socio-Legal, Political, and Empirical Analysis*, edited by Dani Filc, Hagai Boas, Nadav Davidovitch, Shai J. Lavi, and Yael Hashiloni-Dolev, 97–116. Cambridge: Cambridge University Press. https://doi.org/10.1017/9781316671986.006.

Mullin, Emily. 2024. "This Brain Implant Lets People Control Amazon Alexa With Their Minds." *Wired*, September 2024. https://www.wired.com/story/synchron-amazon-alexa-brain-computer-interface-bci/.

Nugent, Selin E., and Susan Scott-Parker. 2022. "Recruitment AI Has a Disability Problem: Anticipating and Mitigating Unfair Automated Hiring Decisions." In *Towards Trustworthy Artificial Intelligent Systems*, edited by Maria Isabel Aldinhas Ferreira and Mohammad Osman Tokhi, 85–96. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-031-09823-9_6.

Ouellette, Alicia. 2011. *Bioethics and Disability: Toward a Disability-Conscious Bioethics*. Cambridge Disability Law and Policy Series. Cambridge: Cambridge University Press. https://doi.org/10.1017/CBO9780511978463.

Patrick-Krueger, K. Michelle, Ian Burkhart, and Jose L. Contreras-Vidal. 2024. "The State of Clinical Trials of Implantable Brain–Computer Interfaces." *Nature Reviews Bioengineering*, September. https://doi.org/10.1038/s44222-024-00239-5.

Perez, Caroline Criado. 2019. *Invisible Women: The Sunday Times Number One Bestseller Exposing the Gender Bias Women Face Every Day*. Random House.

Sample, Matthew, Sebastian Sattler, Wren Boehlen, and Eric Racine. 2023. "Brain-Computer Interfaces, Disability, and the Stigma of Refusal: A Factorial Vignette Study." *Public Understanding of Science* 32 (4): 522–42. https://doi.org/10.1177/09636625221141663.

Schmid, J. R., O. Friedrich, S. Kessner, and R. J. Jox. 2021. "Thoughts Unlocked by Technology—a Survey in Germany About Brain-Computer Interfaces." *NanoEthics* 15 (3): 303–13. https://doi.org/10.1007/s11569-021-00392-w.

Schroeder, Doris, Kate Chatfield, Roger Chennells, Hazel Partington, Joshua Kimani, Gillian Thomson, Joyce Adhiambo Odhiambo, Leana Snyders, and Collin Louw. 2024. "Leaving No One Behind in Research, and the Protection-Inclusion Dilemma for Vulnerable Groups." In *Vulnerability Revisited: Leaving No One Behind in Research*, edited by Doris Schroeder, Kate Chatfield, Roger Chennells, Hazel Partington, Joshua Kimani, Gillian Thomson, Joyce Adhiambo Odhiambo, Leana Snyders, and Collin

Louw, 1–23. Cham: Springer Nature Switzerland. https://doi.org/10.1007/978-3-031-57896-0_1.

Stoetzler, Marcel, and Nira Yuval-Davis. 2002. "Standpoint Theory, Situated Knowledge and the Situated Imagination." *Feminist Theory* 3 (3): 315–33. https://doi.org/10.1177/146470002762492024.

Stoljar, Natalie. 2024. "Feminist Perspectives on Autonomy." In *The Stanford Encyclopedia of Philosophy*, edited by Edward N. Zalta and Uri Nodelman, Summer 2024. Metaphysics Research Lab, Stanford University. https://plato.stanford.edu/archives/sum2024/entries/feminism-autonomy/.

Stuijvenberg, Odile C. van, Marike L. D. Broekman, Samantha E. C. Wolff, Annelien L. Bredenoord, and Karin R. Jongsma. 2024. "Developer Perspectives on the Ethics of AI-Driven Neural Implants: A Qualitative Study." *Scientific Reports* 14 (1): 7880. https://doi.org/10.1038/s41598-024-58535-4.

Šveřepa, Milan. 2021. "Information for All: European Standards for Making Information Easy to Read and Understand." *Inclusion Europe* (blog). October 6, 2021. https://www.inclusion-europe.eu/easy-to-read-standards-guidelines/.

The Artificial Intelligence Ethics Subcommittee of the National Science and Technology Ethics and Commission. 2024. "Ethics Guidelines for Brain-Computer Interface Research." Translated by Ben Murphy. The Chinese Ministry of Science and Technology.

Thong, Ivan SK, Meng Yee Foo, Min Yi Sum, Benjamin Capps, Tih-Shih Lee, Calvin Ho, and Kang Sim. 2016. "Therapeutic Misconception in Psychiatry Research: A Systematic Review." *Clinical Psychopharmacology and Neuroscience* 14 (1): 17–25. https://doi.org/10.9758/cpn.2016.14.1.17.

Tyson, Lee Rainie, Cary Funk, Monica Anderson and Alec. 2022. "6. Public Cautious about Enhancing Cognitive Function Using Computer Chip Implants in the Brain." *Pew Research Center* (blog). March 17, 2022. https://www.pewresearch.org/internet/2022/03/17/public-cautious-about-enhancing-cognitive-function-using-computer-chip-implants-in-the-brain/.

UNESCO. 2025. "Draft Text of the Recommendation on the Ethics of Neurotechnology." In . Intergovernmental Meeting of Experts (Category II) Related to a Draft UNESCO Recommendation on the Ethics of Neurotechnology, Paris, 2025: UNESCO Digital Library. https://unesdoc.unesco.org/ark:/48223/pf0000393395.

Valeriani, Davide, Caterina Cinel, and Riccardo Poli. 2019. "Brain–Computer Interfaces for Human Augmentation." *Brain Sciences* 9 (2): 22. https://doi.org/10.3390/brainsci9020022.

World Medical Association. 2013. "World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects." *JAMA* 310 (20): 2191–94. https://doi.org/10.1001/jama.2013.281053.

———. 2025. "World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Participants." *JAMA* 333 (1): 71–74. https://doi.org/10.1001/jama.2024.21972.

Wylie, Alison, and Sergio Sismondo. 2001. "Standpoint Theory, in Science." In *International Encyclopedia of the Social and Behavioral Sciences (Second Edition)*, edited by James Wright, 324–30. Elsevier. https://philarchive.org/rec/SISSTI.

Yehya, Nadine A. 2024. "New Brain-Computer Interface Allows Man with ALS to 'Speak' Again." *UC Davis Health News*, August 14, 2024. https://health.ucdavis.edu/news/headlines/new-brain-computer-interface-allows-man-with-als-to-speak-again/2024/08.

APPENDICES

Appendix 1: Ethical Review Approval Letter

CEU CENTRAL EUROPEAN UNIVERSITY

Ethical Review Approval Letter

Vienna, February 4,2025

To whom it may concern,

We are pleased to confirm that the following research project:

A Disability-Centered Approach to Research Ethics: The Case of Therapeutic Misconception Risks in Brain-Computer-Interfaces Trials

Researcher: Vy Nguyen

has been approved, following the ethical research review process of the Political Science Department of Central European University (CEU), as performed by the Department's ad-hoc Ethical Research Committee.

The decision of the Ethical Research Committee is valid for the research as described, for the duration of the project.

Based on the documents provided by the researcher, the Ethical Research Committee specifically offers:

- Approval of procedures for identification and recruitment of research participants.
- Approval of procedures ensuring that informed consent will be obtained, including the possibility for withdrawing consent;
- Approval of procedures for safeguarding confidentiality and anonymity

Monitoring of the project will be in line with the ethical procedures established by CEU, which are under permanent observation and review.

Zsolt Enyedi
Member of the ad-hoc Ethical Research Committee of the Political Science Department, Central European University

Judit Sándor
Member of the ad-hoc Ethical Research Committee of the Political Science Department, Central European University

Quellenstraße 51 | 1100 Vienna | Austria

Appendix 2: List of Contacted Organizations

For each of the 27 European member states, at least 5 organizations were contacted unless a national-level body explicitly agreed to distribute the survey to their member networks. Romania and Sweden are the exceptions where only 4 were contacted, due to technical errors that were discovered only later in the research process. Organizations that confirmed to distribute the survey with their members are noted in the list. For other non-EU countries, at least one organization per country was contacted.

My first priority was contacting organizations or associations representing people with disabilities at the national or regional level. If there is no such body or there is no confirmation from the national-level organizations, I reached out to organizations for people with ALS, spinal cord injuries and brain-stem strokes – the main medical conditions that most real-life BCI clinical trials participants have (Patrick-Krueger, Burkhart, and Contreras-Vidal 2024), as well as organizations for various types of motor, sensory or communicative disabilities; then centers for independent living and disability-related groups.

	Organization	**Country**	**Note**
1	Albanian Disability Rights Foundation	Albania	
2	AMIDA	Andorra	
3	BIZEPS – Center for Independent Living	Austria	
4	Wheelchair active – Association of Wheelchair Users in Austria	Austria	
5	Multiple Sclerosis Society Vienna	Austria	
6	Austrian Multiple Sclerosis Society	Austria	
7	Austrian Disability Council	Austria	
8	Belgian National League for Multiple Sclerosis	Belgium	
9	Belgian Disability Forum	Belgium	
10	Esenca	Belgium	
11	Kannet	Belgium	
12	Gamp	Belgium	
13	The Association of the Blind in Sarajevo	Bosnia Herzegovina	
14	Center for Independent Living Bulgaria	Bulgaria	
15	The Union of the Disabled People in Bulgaria	Bulgaria	
16	Bulgarian Association For Neuromuscular Diseases	Bulgaria	
17	National Council of People with Disabilities in Bulgaria	Bulgaria	
18	National Association Of The Deafblind People In Bulgaria	Bulgaria	
19	Zajednica spinalno ozlijeđenih	Croatia	
20	The Croatian Association of Disabled Workers' Associations (HSUIR)	Croatia	
21	Croatian Federation of Dystrophic Societies - SDDH	Croatia	
22	Croatian Federation of Associations of Persons with Physical Disability	Croatia	

23	Croatian Association of Paraplegics and Tetraplegics	Croatia	
24	Cyprus Paraplegic Organization	Cyprus	
25	Cyprus Confederation of Organisations of the Disabled	Cyprus	Agreed to distribute
26	Muscular Dystrophy Association of the Czech Republic	Czech	
27	Asociace POLIO	Czech	
28	Apropo	Czech	
29	Czech Paraplegic Association – CZEPA	Czech	
30	CEREBRUM – association of people with brain injuries and their families	Czech	
31	AVAZ – Association of Wheelchair Users and the Physically and Mentally Disabled	Czech	
32	Kosatec Center, Ltd.	Czech	
33	e-Inclusion	Czech	
34	ParaCENTER Fenix	Czech	
35	PARENT PROJECT	Czech	
36	Trend Wheelchair Association Olomouc	Czech	
37	Association of the Physically Disabled in the Czech Republic	Czech	
38	Disabled Peoples Organisation Denmark	Denmark	Declined
39	Danish Disability Association	Denmark	
40	The Danish Multiple Sclerosis Society	Denmark	
41	Muscular Dystrophy Foundation	Denmark	
42	Polio Association	Denmark	
43	Estonian Aphasia Association	Estonia	
44	Estonian Multiple Sclerosis Association	Estonia	
45	Estonian Musculoskeletal Society	Estonia	
46	Estonian Association of People with Disabilities	Estonia	
47	Estonian Chamber of Disabled People	Estonia	
48	The Threshold Association	Finland	
49	The organisation of Persons with Disabilities in Ålands	Finland	
50	The Federation of Swedish-speaking Disabled in Finland	Finland	
51	The Finnish Association of People with Physical Disabilities	Finland	
52	Finnish Musculoskeletal Association	Finland	
53	Finnish Neuro Society	Finland	
54	Spinal Cord Injury Association Akson	Finland	
55	Finnish Disability Forum	Finland	
56	Parvis	France	
57	French Cerebral Palsy Federation	France	
58	Groupe polyhandicap France	France	
59	Federation of the Blind and Partially Sighted of France	France	
60	French League Against Multiple Sclerosis	France	
61	The Coalition for Independent Living Georgia	Georgia	

62	German Multiple Sclerosis Society	Germany	
63	Federal Association of Self-Help for the Physically Disabled	Germany	
64	Federal Association for Physically and Multiple-Disabled People	Germany	
65	Advocacy Group for Independent Living in Germany — ISL	Germany	
66	General Association of People with Disabilities in Germany	Germany	
67	Perpato Association	Greece	
68	Independent Living Organization of Greece - i-living	Greece	
69	Dear The National Confederation of Disabled People Greece	Greece	
70	Paraplegic Association of Drama Prefecture	Greece	
71	Panhellenic Association of Paraplegics and Physically Disabled People	Greece	
72	Association of Paraplegics and Motorly Disabled People of Pella Prefecture	Greece	
73	Hungarian National Council of Federations of People with Disabilities	Hungary	Agreed to distribute
74	The Organisation of Disabled in Iceland	Iceland	
75	Independent Living Movement Ireland	Ireland	
76	Irish Wheelchair Association	Ireland	Declined due to data policy
77	The Centre for Independent Living Blanchardstown	Ireland	
78	The Carlow Centre for Independent Living	Ireland	
79	Centre for Independent Cork	Ireland	
80	Donegal Centre for Independent Living	Ireland	
81	Galway Centre for Independent Living	Ireland	
82	Centre for Independent Living Kilkenny	Ireland	
83	Longford Centre for Independent Living	Ireland	
84	Centre for Independent Living Offaly	Ireland	
85	Centre for Independent Living Sligo	Ireland	
86	Tipperary Centre for Independent Living	Ireland	
87	Centre for Independent Living Waterford	Ireland	
88	Centre for Independent Living West Limerick	Ireland	
89	Centre for Independent Living Westmeath	Ireland	
90	Centre for Independent Living Wexford	Ireland	
91	The Crann Centre CLG	Ireland	
92	Irish Motor Neurone Disease Association	Ireland	
93	Muscular Dystrophy Ireland	Ireland	
94	Spinal Injuries Ireland	Ireland	
95	Disability Federation Ireland	Ireland	
96	Independent Living Association ONLUS	Italy	
97	Italy Disability Forum	Italy	
98	UILDM - Italian Union for the Fight against Muscular Dystrophy	Italy	

99	Associazione Italiana Sclerosi Multipla	Italy	
100	Associazione Vita Indipendente Umbria	Italy	
101	independent L.	Italy	
102	Kosovo Disability Forum	Kosovo	
103	Apeirons	Latvia	
104	The Latvian Umbrella Body for Disability Organisations	Latvia	
105	Talsi Disabled People's Association	Latvia	
106	Gulbene County Disabled Persons Association	Latvia	
107	MOTUS VITA	Latvia	
108	Liechtensteiner Behinderten Verband	Liechtenstein	
109	Lithuanian Disability Forum	Lithuania	Agreed to distribute
110	The Luxembourg National Disability Council	Luxembourg	
111	Cerebral Palsy Luxembourg	Luxembourg	
112	Kräizbierg	Luxembourg	
113	Wäertvollt Liewen	Luxembourg	
114	ZEFI asbl – Zesumme fir Inklusioun (Ensemble pour l'Inclusion Asbl)	Luxembourg	
115	Malta Federation of Organisations Persons with Disability	Malta	Agreed to distribute
116	The Association of Entrepreneurs with Disabilities of the Republic of Moldova	Moldova	
117	Association Alliance of Organizations for Persons with Disabilities from Moldova	Moldova	
118	Centre for the Rights of Persons with Disabilities Moldova	Moldova	
119	The Monegasque Association of the Motorly Disabled	Monaco	
120	the Association of Youth with Disabilities of Montenegro	Montenegro	
121	Ieder(in)	Netherlands	
122	ALS Netherlands	Netherlands	
123	Ataxia Association	Netherlands	
124	CP Nederland	Netherlands	
125	Duchenne Muscular Dystrophy	Netherlands	
126	Dutch Spinal Cord Injury Organization	Netherlands	
127	National Council of Disability Organisations of North Macedonia	North Macedonia	
128	Uloba	Norway	
129	Disabled Youth Norway	Norway	
130	The Norwegian Federation of Organisations of Persons with Disabilities	Norway	
131	National Association for the Combined Visually and Hearing Impaired	Norway	
132	Norwegian Muscular Dystrophy Association (FFM)	Norway	
133	The Association for Amputees, Dysmelists and Orthosis Users	Norway	

134	Normal Prospects	Poland	
135	Polish Disability Forum	Poland	
136	Karkonosze Regional Assembly of the Disabled	Poland	
137	Association Institute for Independent Living	Poland	
138	TUS Foundation	Poland	
139	Portuguese National Confederation of Organisations of Disabled People	Portugal	
140	Federation of Portuguese Cerebral Palsy Associations	Portugal	
141	NOVAMENTE – Association for the Support of Traumatic Brain Injury Sufferers and Their Families	Portugal	
142	The Portuguese Neuromuscular Association	Portugal	
143	National Multiple Sclerosis Association	Portugal	
144	National Disability Council of Romania	Romania	
145	Romanian Muscular Dystrophy Association	Romania	
146	Association of People with Neuromotor Handicapped in Romania	Romania	
147	Romanian Association of the Blind	Romania	
148	Attiva-Mente	San Marino	
149	The National organization of persons with disabilities of Serbia	Serbia	
150	Belasý motýľ o. z.	Slovakia	
151	Slovak Disability Forum	Slovakia	
152	Organization of Muscular Dystrophies in the Slovak Republic (OMD in the Slovak Republic)	Slovakia	
153	Slovak Association of the Disabled (SZZP)	Slovakia	
154	Slovak Association of the Physically Disabled (SZTP)	Slovakia	
155	Association Of Paraplegics Of Slovenia	Slovenia	
156	Slovenian Dystrophic Society	Slovenia	
157	The Multiple Sclerosis Association of Slovenia	Slovenia	
158	Slovenian Amputee Association	Slovenia	
159	Slovenian Association of the Deaf-Blind DLAN	Slovenia	
160	VIgalicia - Independent Living Office of Galicia	Spain	
161	COCEMFE. Spanish Confederation of People with Physical and Organic Disabilities	Spain	
162	ASPACE	Spain	
163	the Spanish Brain Injury Association	Spain	
164	The Spanish Committee of Representatives of People with Disabilities	Spain	
165	Newcomers with Disabilities	Sweden	Agreed to distribute
166	Swedish Brain Injury Association	Sweden	
167	Neuroförbundet	Sweden	
168	Swedish Disability Rights Federation	Sweden	
169	The European Spinal Cord Injury Federation	Switzerland	Agreed to distribute
170	Swiss Multiple Sclerosis Society	Switzerland	

171	SPECTRUM Centre for Independent Living	UK	
172	Leeds Disabled People's Organisation	UK	
173	Glasgow Disability Alliance	UK	
174	European alliance of Neuromuscular disorders associations	Europe	
175	Cerebral Palsy – European Communities Association	Europe	
176	European Network on Independent Living	Europe	Agreed to distribute

Appendix 3: Survey Form

The study aims to refine research ethics through a disability-centered perspective. It examines how people with disabilities perceive implantable Brain-Computer Interface (BCI) clinical trials.

Brain-Computer Interface is a technology that uses electrodes implanted on the brain to read brain signals and turn them into commands controlling other devices such as computers, robotic limbs, or speech synthesizers.

Please take the time to read the following information, and contact the researcher if anything is unclear.

Researcher: Vy Nguyen.
Institution: Department of Political Science, Central European University (Austria).
Supervisor: Professor Judit Sandor.

-----[page break]----- [16]

Purpose of the study:

- This study is conducted in partial fulfillment of the Master's Degree program in Political Science at Central European University (CEU), Austria.
- The Ethics Committee of the Political Science Department at CEU has approved this research.

Accessibility:

In case you need a plain language version of the survey, please access this link:
https://qualtrics.ceu.edu/jfe/form/SV_8zSrEgJ1REyjhki

For any accommodation request, please contact the Researcher at nguyen_vy@student.ceu.edu.

Participation conditions:

- To participate in this study, you must be age 18 or above.
- You do NOT need to have participated/ considered participating in any clinical trials, or know about Brain-Computer Interface technology to take the survey.
- If you are legally required to have a representative's consent to enter the survey, please ensure that you obtain their explicit agreement before proceeding.

Potential risks and benefits:

- The potential risks involved in participating are comparable to those experienced while using a computer or mobile phone in conditions of everyday life.
- Participation in this survey is voluntary.

Data storage and protection:

- Your responses are anonymous and kept confidential.

[16] In this Appendix, author's notes, appearing in italics, do not appear on the published survey.

Please do not include your name or any identifying information in your responses.
- You can withdraw your consent at any time before submitting the survey.
  Please note that once the survey is submitted, consent cannot be revoked, as it is impossible to identify which response belongs to you.

Researcher's contact: nguyen_vy@student.ceu.edu.

Your consent:

If you are willing to participate in the study, please click on the 'AGREE' button below. By clicking "AGREE", you acknowledge that:

- You have read and understood what the study is about.
- You have had the opportunity to ask questions and have them answered satisfactorily.
- You agree with the terms of data storage and protection.
- Your participation is voluntary.
  You are free to withdraw your consent at any time before submitting the survey.
- ***In case a legal representative's consent is required***, you and the representative both have read and agreed to participate in the survey.

□ AGREE to participate in the survey
□ DISAGREE to participate in the survey *[the survey ends if this option is chosen]*

-----[page break]-----
All questions are required unless stated otherwise.

1. **How old are you?**
   □ Under 18 *[the survey ends if this option is chosen]*
   □ 18-24 years old
   □ 25-34 years old
   □ 35-44 years old
   □ 45-54 years old
   □ 55-64 years old
   □ 65+ years old

-----[page break]-----

2. **In which country do you currently reside?**
   [choose answer from a drop-down menu of country names]

3. **How do you describe yourself?**
   □ Male
   □ Female
   □ Non-binary / third gender
   □ Prefer to self-describe: *[text input]*
   □ Prefer not to say

-----[page break]-----

4. **What is the highest level of education you have completed?**
   □ Some Primary

- Completed Primary School
- Some Secondary
- Completed Secondary School
- Vocational or Similar
- Some University but no degree
- University Bachelors Degree
- Graduate or professional degree (MA, MS, MBA, PhD, JD, MD, DDS)
- Prefer not to say

-----[page break]-----

- The study adopts the social model of disability, however, some medical information of your disability is needed.
- This is because admission to most brain-computer-interface clinical trials depends on specific medical conditions.
- In the following questions, "Impairment" refers to the medical conditions that, when interacting with social barriers, result in "Disability".

5. How would you describe your type of disability? Choose all that apply.
- **Sensory**: concerning senses such as vision, hearing, touch, taste, smell, etc.
- **Motor**: concerning movement of body parts, muscle control, etc.
- **Communicative**: concerning the ability to receive, send or comprehend verbal/ non-verbal/ written information, etc.

6. How long have you had this disability? Please also specify if it is from birth. For example: 20 years, from birth.
[free text answer]

-----[page break]-----

7. What is the main medical cause of your impairment?
- Brain-stem stroke
- Neurodegenerative disorders (including ALS, etc.)
- Injuries (including spinal-cord injury, etc.)
- Prefer not to say
- Others: *[text input]*

8. Is there medical treatment available that could either reverse or lessen the effects of your impairment?
- No
- I don't know
- Yes

-----[page break]-----

In this section, you will be presented with <u>the case of Alex</u>. Please read it carefully before proceeding to the questions.

Alex is a 50-year-old who has had *[answer chosen for Question 5 will be inserted here]* disability for several years.

Alex has lost the ability to carry most daily activities without the help of assistive devices, and often requires assistance of another person.

Alex's independence is limited to a significant degree due to the disability.

Recently, Alex has heard about a clinical trial for a new technology called Brain-Computer Interface (BCI).

This innovative technology is designed to help people with disabilities live more independently. It is not yet available on the market and is still being tested in clinical trials.

_____

A. How this new BCI technology works

- The technology is developed to help people with sensory, communication, or motor disability regain some control over their functioning.
- As part of the trial, Alex will first need to undergo surgery to have an electrode implanted on the brain surface.
- This implanted electrode detects brain signals and translates them into commands on an external device (such as a computer, a speech synthesizer, prosthetic limbs, or an electrical stimulation device), allowing users to operate the external device using only their thoughts.
- As such, this technology might help Alex be more independent.

B. Using BCI technology

- Throughout the trial, Alex will be asked to perform specific tasks that help researchers collect relevant data from the brain's activities and evaluate how well the device is working.
- Tasks performed in the trials may not be the same as everyday tasks.
  They may include things like pointing a cursor and clicking, making body movement, reaching and grasping objects.

C. Time commitment

- The study requires regular training and testing sessions.
- The overall duration of the trial varies, but on average, it may last up to three years.

D. Other information

Alex looks for more information and finds that:

- Similar trials have been conducted before.
- There is limited public information about the progress and outcome of past trials.
- Most similar trials have been conducted by research groups or non-profits.
  Recently, some corporations have started their own trials.
- Media coverage often portrays BCI as a breakthrough for people with disabilities, as it gives them more independence and control.

9. **On a scale of 1 to 5 (1 = Definitely not; 5 = Definitely yes)**[17]**, to what extent do you think the following statements are correct?**
   [The order of these statements was randomized for each respondent]

   - (9A) When they design such BCI trials, researchers must ensure that each participant will receive the best possible device/ setup for their individual needs, similar to the personalized care they would receive from their primary healthcare provider.
   - (9B) In the BCI trials, researchers will always try to give each participant the device or setup that best addresses their unique needs.
   - (9C) The trial's purpose is to provide the best solution (in this case - assistive device) available for Alex and other participants.
   - (9D) The most important task for the researcher is to ensure that the trial will help its participants.
   - (9E) The treatment/solution that Alex receives by participating in the trial is probably the best option for Alex.
   - (9F) By taking part in a clinical trial, people like Alex will receive the best solution for their needs.

-----[page break]-----

10. **On a scale of 1-5 (1 = Definitely not; 5 = Definitely yes), to what extent do you think that <u>Alex</u> should join the trial?**

-----[page break]-----

11. **Brielfy explain your answer "***(the answer chosen for the previous question shows here)***"?**
    What are the main elements that make you think so?
    [free text answer, optional]

-----[page break]-----

12. **On a scale of 1-5 (1 = Definitely not; 5 = Definitely yes), to what extent would <u>you</u> consider joining the trial?**

-----[page break]-----

13. **Brielfy explain your answer"***(the answer chosen for the previous question shows here)***"?**
    What are the main elements that make you think so?
    [free text answer, optional]

-----[page break]-----

[17] The answer options for all questions using the same "1-5 Definitely not to Definitely yes" scale: 1 – Definitely not, 2 – Probably not, 3 – May or may not, 4 – Probably yes, 5 – Definitely yes.

14. On a scale of 1-5 (1 = Definitely not; 5 = Definitely yes), to what extent do you think it is good that BCI clinical trials are only open to participants with disabilities?

-----[page break]-----

15. Have you ever participated in an experimental study/ clinical trial before?

- No
- Yes

[If "Yes" is chosen, this additional question shows up]

15.2 On a scale of 1-5 (1 = Extremely negative; 5 = Extremely positive), how do you rate your overall experience of participating in that experimental study/ clinical trial?

- 1 - Extremely negative
- 2 - Somewhat negative
- 3 - Neither positive nor negative
- 4 - Somewhat positive
- 5 - Extremely positive

-----[page break]-----

16. ***Now think about <u>your own experience.</u>***
On a scale of 1 to 5 (1 = Definitely not; 5 = Definitely yes), to what extent are the following statements apply to you?

- (16A) I feel sufficiently supported by the care & accommodations services available where I live.
- (16B) I have a good support network from family & friends.

-----[page break]-----

17. If you would like to leave a comment or message for the researcher, please do so below. *(optional)*
The survey will be submitted after you click the Arrow/ Next button.

[end of survey]

Appendix 4: Survey Form in Plain Language

The study looks at research ethics
from the view of people with disabilities.

It studies how people with disabilities feel
about Brain-Computer Interface clinical trials.

Brain-Computer Interface is a technology that
uses electrodes implanted on the brain
to read brain signals
and turn them into commands controlling other devices|
such as computers, robotic limbs, or speech synthesizers.

A clinical trial is a study that tests new medical treatments or interventions.
It checks if they are safe for human use.

Please take the time to read the following information.
Contact the researcher if anything is unclear.

Researcher: Vy Nguyen.
Institution: Department of Political Science, Central European University (Austria).
Supervisor: Professor Judit Sandor.

-----[page break]----- [18]

Purpose of the study:

- This study is part of a Master's Degree in Political Science
  at Central European University (CEU), Austria.
- The Ethics Committee of the Political Science Department at CEU
  has approved this research.

Accessibility:

- This survey version is made in plain language.
- If you need any support to take part in the survey,
  please email the Researcher: nguyen_vy@student.ceu.edu.

Who can take part:

- You must be 18 years or older.
- You do not need to have joined a clinical trial,
  or known about Brain-Computer Interface technology before.
- If you need a representative's consent to enter the survey,
  please make sure to get their explicit agreement before starting.

Potential risks and benefits:

[18] In this Appendix, author's notes, appearing in italics, do not appear on the published survey.

- The risks of this survey are the same as using a computer or phone in daily life.
- Participation in this survey is voluntary.

Data and privacy:

- Your answers are anonymous and will be kept confidential.
- Do not include your name or any confidential information.
- You can withdraw your consent anytime **before submitting** the survey.
- After you submit, your answers cannot be removed because they are not linked with your name.

If you have any questions or request,
contact the Researcher: nguyen_vy@student.ceu.edu.

Your consent:
If you want to participate in the study,
please click "AGREE".

By clicking “AGREE”,
you confirm that:

- You understand what the study is about.
- You have had the opportunity to ask the researchers any questions and get answers.
- You agree with how your data is stored and used.
- You know that participation is your voluntary choice.
- You can stop anytime **before submitting** the survey.
- If you need a representative's consent to participate, both you and your representative agree with the above.

□ AGREE to participate in the survey

□ DISAGREE to participate in the survey *[the survey ends if this option is chosen]*

-----[page break]-----
All questions are required unless stated otherwise.

1. **How old are you?**
   - □ Under 18 *[the survey ends if this option is chosen]*
   - □ 18-24 years old
   - □ 25-34 years old

- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65+ years old

-----[page break]-----

2. **In which country do you currently reside?**
   [choose answer from a drop-down menu of country names]

3. **How do you describe yourself?**
   - Male
   - Female
   - Non-binary / third gender
   - Prefer to self-describe: *[text input]*
   - Prefer not to say

-----[page break]-----

4. **What is the highest level of education you have completed?**
   - Some Primary
   - Completed Primary School
   - Some Secondary
   - Completed Secondary School
   - Vocational or Similar
   - Some University but no degree
   - University Bachelors Degree
   - Graduate or professional degree (MA, MS, MBA, PhD, JD, MD, DDS)
   - Prefer not to say

-----[page break]-----

- The study follows the social model of disability,
  but this section will ask some medical information of your disability.
- This is because joning most brain-computer-interface trials
  depends on specific medical conditions.
- In this part,
  "impairment" means the medical conditions
  that when combined with social barriers,
  cause "disability".

5. **How would you describe your type of disability? Choose all that apply.**
   - **Sensory**: concerning senses such as vision, hearing, touch, taste, smell,…
   - **Motor**: concerning movement of body parts, muscle control,…
   - **Communicative**: concerning the ability to receive, send or comprehend verbal/ non-verbal/ written information,…

6. **How long have you had this disability?**
   Please also specify if it is from birth.
   For example: 20 years, from birth.

[free text answer]

-----[page break]-----

7. What is the main medical cause of your impairment?

- Brain-stem stroke
- Neurodegenerative disorders (including ALS, etc.)
- Injuries (including spinal-cord injury, etc.)
- Prefer not to say
- Others: *[text input]*

8. Is there medical treatment available that could either reverse or lessen the effects of your impairment?

- No
- I don't know
- Yes

-----[page break]-----

This section tells you <u>the story of Alex</u>.
Please read it carefully
before answering the questions.

Alex is a 50-year-old
who has had *[answer chosen for Question 5 will be inserted here]* disability for several years.

Alex cannot do many daily activities
without assistive devices,
and often needs help from another person.
Thus, the disability has limited Alex's independence
to a significant degree.

Recently, Alex learned about a clinical trial
for a new technology.
The technology is called Brain-Computer Interface.

This technology helps people with disabilities
live more independently.
This technology is not yet available to the public.
They are still testing this technology in clinical trials.

A. How brain-computer-interface technology works

Researchers develop this technology
to help people with sensory, communication, or motor disability.
It gives them more control and independence.

As part of the trial,
Alex will go through a brain surgery
to implant an electrode on the brain.

This electrode reads brain signals
and turns them into commands.
These commands can control things like:

- Computer cursor;
- Speech synthesizer (device that translates text to speech);
- Prosthetic limbs;
- Electrical stimulation device;
- Devices that stimulate sensation.

With this technology,
Alex can use such devices only by thinking.
Therefore, Alex may gain more independence.

B. Using this technology

During the trial, Alex will be asked to do certain tasks.
These tasks help researchers
collect brain data
and understand how well the device works.

The tasks may differ from daily activities.
For example, the task may be:

- Moving and clicking computer cursor.
- Making body movements.
- Reaching and grasping objects.

C. Time commitment

The trial requires regular training and testing sessions.
The trial duration varies,
it may last up to 3 years.

D. Other information

Alex looks for more information and finds that:

- There are similar trials before.
  There is little public information on their results.
- Research groups or non-profits have done most trials.
  Recently some private companies are also running trials.

- The media says Brain-Computer Interface technology can help people with disability
  gain more independence and control in their life.

9. Do you think the following statements are correct?
Rate from 1 to 5[19]:
1 = Definitely not
5 = Definitely yes
[The order of these statements was randomized for each respondent]

- (9A) When they design such trials, researchers must ensure that each participant gets the best Brain-Computer Interface device, or setup for their individual needs.
  Similar to what they would get from their own healthcare provider.
- (9B) In the trials,
  researchers will always try to
  give each person the Brain-Computer Interface device, or setup that is best for the person's needs.
- (9C) The purpose of the trial is
  to give Alex and other participants
  the best possible treatment or solution for their needs.
  For example, this could be the best assistive device.
- (9D) The most important task for the researcher is
  to ensure that the trial will help its participants.
- (9E) The treatment or solution that Alex receives in the trial
  is probably the best option for Alex.
- (9F) By taking part in a clinical trial,
  people like Alex will receive the best solution for their needs.

-----[page break]-----

10. Do you think that <u>Alex</u> should join the trial?
Rate from 1 to 5:
1 = Definitely not
5 = Definitely yes

-----[page break]-----

11. Brielfy explain your answer "*(the answer chosen for the previous question shows here)***".**
What elements make you think so?
[free text answer, optional]

-----[page break]-----

[19] The answer options for all questions using the same "1-5 Definitely not to Definitely yes" scale: 1 – Definitely not, 2 – Probably not, 3 – May or may not, 4 – Probably yes, 5 – Definitely yes.

12. Would <u>you</u> consider joining the trial?
Rate from 1 to 5:
1 = Definitely not
5 = Definitely yes

-----[page break]-----

13. Brielfy explain your answer"*(the answer chosen for the previous question shows here)***".**
What elements make you think so?
[free text answer, optional]

-----[page break]-----

14. Is it good that Brain-Computer Interface clinical trials are ONLY open to participants with disabilities?
Rate from 1 to 5:
1 = Definitely not
5 = Definitely yes

-----[page break]-----

15. Have you ever
participated in an experimental study/ clinical trial before?
- No
- Yes

[If "Yes" is chosen, this additional question shows up]
15.2. How do you rate your overall experience
in that experimental study/ clinical trial?
Rate from 1 to 5:
1 = Extremely negative
5 = Extremely positive

- 1 - Extremely negative
- 2 - Somewhat negative
- 3 - Neither positive nor negative
- 4 - Somewhat positive
- 5 - Extremely positive

-----[page break]-----

16. *Now think about <u>your own experience.</u>*
How much do these following statements apply to you?
Rate from 1 to 5:
1 = Definitely not
5 = Definitely yes

- (16A) I feel sufficiently supported by the care & accommodations services available where I live.
- (16B) I have a good support network from family & friends.

-----[page break]-----

17. If you would like to leave a comment or message for the researcher, please do so below. *(optional)*
The survey will be submitted after you click the Arrow/ Next button.

[end of survey]

Appendix 5: Demographics and Details of Survey Respondents

Respondent	Country	Age group	Gender	Education level	Therapeutic misconception		Rating of support quality (1 – Insufficient, 5 – Sufficient)	
					Total point	Risk category	Local community	Personal relationships
1	Lithuania	35-44	Female	Graduate or professional degree	25	Moderate	1	4
2	Finland	35-44	Female	Graduate or professional degree	12	Low	3	4
3	Slovakia	25-34	Female	University Bachelors Degree	19	Moderate	4	5
4	Serbia	25-34	Female	University Bachelors Degree	28	High	1	3
5	Iceland	18-24	Female	Some Secondary	24	Moderate	2	2
6	Italy	55-64	Male	Some University but no degree	29	High	3	2
7	Moldova	35-44	Female	Graduate or professional degree	28	High	2	5
8	Austria	18-24	Female	University Bachelors Degree	23	Moderate	2	2
9	Belgium	25-34	Female	Graduate or professional degree	12	None	1	4
10	Netherlands	25-34	Male	University Bachelors Degree	26	High	5	5
11	Netherlands	35-44	Female	Graduate or professional degree	21	Moderate	3	5

12	Lithuania	25-34	Female	Graduate or professional degree	18	Low	1	4
13	Malta	55-64	Female	Completed Secondary School	20	Moderate	2	3
14	Serbia	18-24	Female	University Bachelors Degree	26	High	2	5
15	Serbia	35-44	Female	University Bachelors Degree	26	High	1	5
16	Slovakia	25-34	Male	Graduate or professional degree	24	Moderate	5	5
17	Lithuania	35-44	Male	University Bachelors Degree	19	Low	4	4
18	Italy	25-34	Female	University Bachelors Degree	21	Low	1	4
19	Italy	18-24	Female	University Bachelors Degree	22	Low	3	4
20	Croatia	25-34	Female	Graduate or professional degree	25	High	4	4
21	Switzerland	25-34	Female	University Bachelors Degree	15	Low	2	3
22	Greece	35-44	Male	University Bachelors Degree	22	Moderate	1	4
23	San Marino	55-64	Male	Some Secondary	27	High	4	4
24	Italy	65+	Male	Graduate or professional degree	28	High	1	3
25	Slovakia	35-44	Male	Completed Secondary School	24	High	4	5
26	Portugal	35-44	Male	Some University but no degree	24	Moderate	4	5
27	Luxembourg	35-44	Male	University Bachelors Degree	24	Moderate	2	5

28	Serbia	18-24	Female	Some University but no degree	25	Moderate	4	5
29	France	18-24	Male	Completed Secondary School	23	Moderate	3	4
30	Austria	25-34	Female	Graduate or professional degree	17	Low	2	3
31	Austria	25-34	NA	University Bachelors Degree	19	Low	2	4
32	Denmark	65+	Female	Graduate or professional degree	24	High	5	5