



Experience, Embodiment, and Post-Trial Obligations in Brain-Based Visual Prosthesis Research

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read standard print, and drive independently. They also expressed concerns about the safety and reliability of procedures and emphasized that a worthwhile procedure must not compromise their health or quality of life substantially” (Silverman 2007). Even so, a full 21% of our respondents (n = 58/281) indicated to us that they are unwilling to become sighted at all. Qualitative data showed that for these participants, sight restoration is at best unnecessary and at worst potentially detrimental to them and their quality of life.

Moreover, we found that, “contrary to common stereotypes of the blind, the vast majority of these participants stated or implied that they view themselves as healthy, active members of society just like their sighted counterparts” (Silverman 2007). They work, have families, and enjoy leisure activities, just like anyone else. “Many also stated or implied that while sight would add convenience, gaining sight is relatively unimportant to them compared to preserving their active engagement with life” (Silverman 2007).

We commend Levy et al. for caring to document the attitudes, expectations, and experiences of participants in the Orion VCP Early Feasibility Study and encourage the National Institutes of Health to fund similar research as part of all EFSs. Too often medical researchers, no matter how well-intentioned, proceed with research and development without any insight into the needs, wants, and values of those they are hoping to treat. Treating them as people, first and foremost, would go a long way toward well-stewarded investments in research that aligns with those needs, wants, and values—research that actually matters in the real world.

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Experience, Embodiment, and Post-Trial Obligations in Brain-Based Visual Prosthesis Research

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Levy and colleagues (2024) add to the small but crucial body of work eliciting end-user perspectives on

brain-based visual prostheses (BVPs). Their data reporting interviews with Orion visual cortical

prosthesis trial participants illustrates the importance of engaging with user perspectives in neural device development and neuroethics analysis. One of their main aims is to show how such perspectives “could reveal obligations to participants during and after the trial” (160). While the authors enumerate potential obligations to participants during trials (e.g., consideration and maximization of various types of benefit), post-trial obligations (PTOs) figure less prominently in their results.

PTOs have been discussed in the context of neural implants more broadly and include proposed obligations of ancillary care, continued access to trial devices, and/or explantation of participants who request it (Lázaro-Muñoz et al. 2018). However, much of this literature has focused on therapeutic devices like deep brain stimulators. Consideration of PTOs for early-stage devices like BVPs remains underdeveloped. Here, we identify two interrelated areas that may be fruitful for further examination as BVPs progress. First, we identify an additional type of benefit that may arise in BVP trials. Second, we consider the ways embodiment of the device may emerge through active forms of trial participation. We offer these two considerations in the hope that they may be valuable in directing further examination of PTOs in Levy et al.’s ongoing work and that of other groups like our own.

To begin, we would like to build upon Levy and colleagues’ discussion of the complexity of the relationship between function and benefit of BVPs like Orion. They distinguish two types of benefit: functional and nonfunctional. The former category included the activities (such as those of daily living) in which the device allows a user to engage. Nonfunctional benefits included “altruism, excitement, and hopefulness about technological advancement” (165). Benefits of these two kinds are rightly the foci of Levy et al.’s work given the nascent capabilities of current BVPs.

We would like to suggest, however, a third class of potential benefits: the *intrinsic* benefits of visual experience itself.¹ We draw here from Siewert (2021), who argues at length that conscious experience (including visual experience) often “bring[s] a value of its own to us” independently of what else it enables us to do (3). We tend to enjoy or otherwise value conscious experience, Siewert thinks, in respects that go

beyond its functional usefulness and even when it brings no functional benefit at all.

To illustrate this idea, consider Levy et al.’s participant who described being able to perceive the contrast between the sidewalk and the grass in their neighborhood. Might this participant or others value the perceptual experience of these features of the scene itself, in addition to its role in allowing them to navigate? Would they value the experience of (someday) perceiving this scene in higher resolution or in color, even if it brought no further functional benefit? It is important to gain a greater understanding now of the extent to which such benefits are anticipated and desired by those for whom BVPs are designed, especially given participants’ “high expectations for long-term technological advancement of the technology” (Levy et al. 2024, 162). Participant interest (or lack thereof) in such benefits could be important inputs to design choices that bear primarily on the aesthetic dimensions of the visual experience produced by a device rather than functional utility. Moreover, obligations to maximize potential benefits (both during and after the trial) are plausibly shaped by this type of valued experience.

We now consider, second, the ways BVP users may develop degrees of felt ownership over the device with implications for PTOs. The authors state that Orion trial participants had dedicated themselves to five years of (bi-)weekly training sessions using the system in a lab environment, along with their own independent practice. They report that “the structure of the Orion trial fostered a sense of agency and ownership over the device” (165). Yet they do not elaborate on these experiences or their possible ethical implications in much additional detail.

In the prosthetics literature, ownership and agency have been described as subcomponents of the concept of embodiment (Zbinden, Lendaro, and Ortiz-Catalan 2022). Embodiment has been widely described for limb prostheses, where it is often used as a metric of success (Zbinden, Lendaro, and Ortiz-Catalan 2022), and it is increasingly discussed in the context of motor BCIs. Here the theoretical framework of embodied phenomenology asks “how and to what extent a neuro-engineering device is a tool or can be incorporated as a part of the ‘self’” (Tbalvandany et al. 2019, 232).

To our knowledge, the concept of embodiment has not been described in the context of BVPs or other visual prostheses. In applying it to BVPs, we may draw upon Merleau-Ponty’s description of how

¹While this class would presumably fall under the broad category of non-functional benefit, we believe it is distinct enough from the benefits Levy et al. include under that heading to warrant its own treatment.

sensory integration can occur between a subject and an external object like a cane:

The blind man's cane has ceased to be an object for him, it is no longer perceived for itself; rather, the cane's furthest point is transformed into a sensitive zone, it increases the scope and the radius of the act of touching and has become analogous to a gaze (Merleau-Ponty 1945 [2012], 144).

On Merleau-Ponty's telling, the cane is experienced as an extension of the subject, rather than as an external tool. And it is not only *experienced* in this way, but in fact *is* an extension or part of the subject. We suspect that something similar could occur with sufficiently sophisticated BVPs.

Different experiences of embodiment in BVP research are likely to have divergent ethical implications, including implications for PTO. It presumably might, for example, be more harmful to remove devices at the end of a trial that are experienced as part of internal abilities than those that are less integrated into the user's sense of self. To explore embodiment of BVPs, we can again find a useful example in the case of motor BCIs. Like the Orion trial, many motor BCI trials require extensive training in order for users to learn to work with and control the device. Additionally, sensory feedback mechanisms (e.g., proprioceptive feedback and visual feedback) may be included to enhance user's embodiment of the device, improving control and performance (Tbalvandany et al. 2019). In this way, active embodiment may be not just a consequence of research participation, but a central aim of the research.

The extensive training in the Orion trial displays parallels with the aim of active embodiment in motor BCIs. This kind of training benefits the study, and in the course of doing so may habituate the participant to increasing reliance on the device in order to achieve these study benefits. The burden of extensive training for active embodiment and expected benefits for the study may reveal grounds for PTO based on reciprocity. Levy et al. additionally report that the Orion trial structure contributed to participants taking on roles as active collaborators and in promoting the technology. Building on Henry Richardson's work, Goering, Brown, and Klein (2024) argue that in such neurotechnology trials, *moral entanglements* form between participant and researcher due to the participant's vulnerability, uncompensated risks and burdens, depth of relationship with the research team, and dependence on the researchers.

Embodiment of neural implants also appears to extend beyond motor BCIs. Gilbert, Ienca, and Cook

(2023) present a case study in which a strong relation of "symbiosis" formed between a user and her Neurovista advisory implant for epilepsy. Removal of this device (against the will of the participant) had serious consequences for the user's agential, cognitive, and emotional life. Gilbert et al. rightly ask (though do not answer) the question of whether this might constitute a violation of the recently much-discussed right to *mental integrity*. Zuk (forthcoming) suggests that the case is indeed reasonably interpreted that way, because it is plausible to regard these three types of capabilities (agentive, cognitive, and affective) as jointly constituting mental integrity, and as thus deeply bound up with the intrinsic benefits of experience mentioned above.

This potential violation of mental integrity reveals another possible ground for PTOs for neural devices. Assessments of the extent to which such risks are present in BVP research need to be informed by additional phenomenological accounts of trial participants to enable greater understanding of population-specific vulnerabilities that may exacerbate harms involved in removal of the BVP (particularly if this were to occur against a participant's wishes). Loss of vision in retinitis pigmentosa has been described as emotionally taxing, necessitating adaptation and management of identity, autonomy, and independence (Garip and Kamal 2019). Losing access to artificial visual experiences, even rudimentary ones, may be similarly harmful in virtue of loss of functional, nonfunctional, or intrinsic benefits of visual experience.

We want to close by emphasizing, then, the far-ranging implications of Levy et al.'s claim that participant perspectives can reveal and illuminate PTOs. We have identified several overlapping and mutually reinforcing ways in which they do so, and we hope this will be of service to both Levy et al.'s group and the field more broadly as it continues to grapple with these issues.

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Neglected Stakeholder Perspectives in Qualitative Neural Implant Research

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Neurotechnological advancement hinges on cohesive collaboration among diverse stakeholders, all unified in improving user quality of life. However, identifying the specific individuals who should qualify as stakeholders is a difficult task. An expansive range of expertise and lived experiences can inform device design. Bioengineers may be best positioned to

comment on the durability, biocompatibility, and comfort of the device, clinical investigators on safety, benefit, and the demands of the study protocol, manufacturers on procuring cost-effective materials, and funding agencies on priority setting and societal impact. Integrating the myriad concerns expressed by these stakeholders throughout device research and

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