David Geffen School of Medicine

BRAIN INITIATIVE

Funded by an ethics supplement to *"Early Feasibility Clinical Trial of a Visual Cortical Prosthesis"*, UH3NS103442

Accessibility, user-centered design, and the future of neural interfaces for artificial vision

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Highlights

1. Preliminary data from interviews with visual cortical prosthesis (VCP) trial participants indicates an asymmetry between functionality and benefit. While the device enables users to do specific tasks like detect the boundary between grass and concrete, this does not necessarily translate into a high level of overall benefit in terms of usefulness, usability, and quality of life.
2. The lenses of disability justice, epistemic injustice, and user centered design help interpret this asymmetry and motivate potential solutions.
3. While UX research and user-centered design are common practices in later-stage medical device development, we argue there is both an ethical and design imperative to implement these practices during early development.

Empirical evidence from qualitative ethics study

Background: Participants (n=4) in an early feasibility trial for a visual cortical prosthesis (UH3 NS103442). were interviewed about their experiences using the device, functionality they gained, and their assessments of risk and benefit.

Research question: Does the kind of artificial vision currently enabled by VCPs provide functional abilities that users find useful and beneficial?

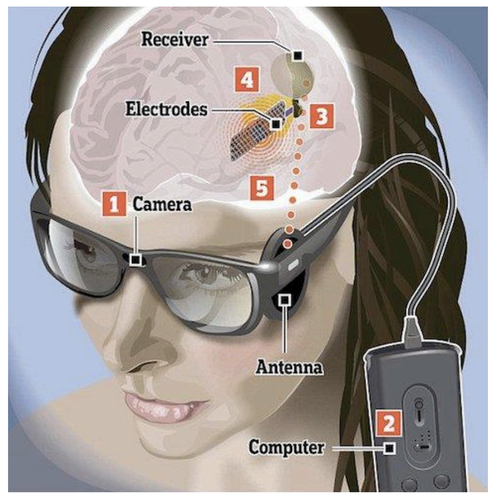
Methods:

- 60-minute semi-structured interviews
- Coded and analyzed using grounded theory

Results:

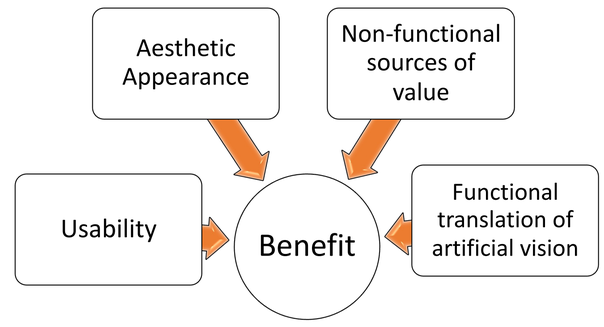
Results suggest *a **distinction between the reported functionality provided by the device and other kinds of value which may impact assessment of benefit, such as an altruistic sense of contributing to technological advancement***.

Participant accounts of functionality and benefit contained divergent claims about the "marginal" utility of the device as well as detailed accounts of how the device enabled them to perform specific tasks, such as detecting the boundary between a concrete sidewalk and grass.



Functionality ≠ Benefit

Components of Benefit



Making Sense of the Asymmetry between Function and Benefit

Disability Justice

The permissibility of VCP research with blind individuals can be linked to two implicitly *ableist* ideas:

- Blind participants have less to lose than non-disabled participants—in other contexts, elective brain implants are impermissible because of the associated risks.
- Blind participants have everything to gain—any marginal visual function is construed as a benefit.

This implies that either:

- The risks of a blind person electing to undergo brain implantation surgery is far outweighed by potential benefit for them or for others, or
- The blind person has "nothing to lose": they only stand to gain benefit because *any sight is better than no sight.*

In either case, the implicitly ableist belief is that unlike other brain research participants, this population has more to gain or less to lose *in virtue of* their blindness.

Further, the relative lack of involvement of visually impaired persons in the development of VCP technologies poses both an ethical and a practical problem: morally, it ignores the plea to include disabled voices in decisions that will affect them, and practically, it leads to the conflation of functionality with beneficiality.

Epistemic Injustice

Epistemic Privilege is the specialized access a person has to certain knowledge by virtue of the subject position they occupy. Both investigators and participants are epistemically privileged in different ways.

Mapping epistemic privilege of VCP users

Knowledge About:	structural oppression faced by disabled individuals related to healthcare system and social infrastructure at large
	the experience of navigating built environments that are not designed for individuals with visual impairments
	what it's like to experience the new sensory modality of artificial vision
	whether, how, and to what extent artificial vision is useful for navigating the built environment
	what it's like to participate in a novel device trial

"The knowledge of patients is usually confined to the private realm and is not readily incorporated into decision making, intervention, design, and policy documents." (Carel & Kidd, 2014)

Incorporating the specialized knowledge of participants throughout the research and design process of VCPs may serve several purposes: 1) resisting epistemic injustice, 2) advancing the goals of disability justice, 3) and improving aspects of the device users find beneficial.

User Centered Design

User centered design (UCD) is an iterative design process that incorporates user feedback during every stage of product design and development. Understanding user needs is central to the development of any technology, but it is especially important in the case of medical devices like visual prostheses. One way this is accomplished is through *user experience (UX) research*.

There are several features of VCP systems that influence users' evaluation of devices:

- The quality of the artificial vision provided by the neural interface
- Other aspects of device system that impact the usability of the device such as the ease of fastening the external components and the aesthetic appearance of the device
- Whether users can integrate VCPs into daily life alongside other assistive technologies (i.e., white cane, screen readers) in a way that adds value beyond what is provided by other devices

UX research is required to learn more about these three areas of user need. While current FDA recommendations address the importance of iterative UCD, the guidelines are quite flexible, and manufacturers typically do not incorporate UX research and UCD until later phases of development.[2] Implementing these practices *earlier*—before and during early feasibility trials—may improve benefits for participants.[3]

Considerations Going Forward

More empirical ethics research to better understand the ways in which blind/visually impaired users value artificial vison based assistive technologies and assess associated risks

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Implementing user experience research and design earlier in device development, i.e., research into external components of device before implantation, integration with other assistive technologies

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Inclusion of blind persons in decision making capacities during all phases of development, i.e., boards of device companies, more formalized feedback channels for participants during feasibility trials

Selected References

1. Carel, H and Kidd, I. J. *Epistemic injustice in healthcare: a philosophical analysis* in Medicine Health Care and Philosophy (2014) 17, 529-540.
2. FDA Guidance Document on Design Controls nor the Quality System Regulations to which it applies (FDA 21 CFR 820.30 and ISO 9001
3. Standards Roadmap: Neurotechnologies for brain-machine interfacing, IEEE SA Industry Connections Activity No. IC17-007