

# The ethics of brain-based visual prostheses: researcher views

Peter Zuk and Gabriel Lázaro-Muñoz

Center for Bioethics, Harvard Medical School

## Introduction

- Brain-based visual prostheses (BBVPs) aim to restore a functional analogue of sight for people with acquired blindness.
- The field raises important **ethical and conceptual questions**[1][2] but has received little attention from neuroethicists compared to other invasive neurotechnologies.
- We are currently interviewing **researchers conducting work related to BBVPs** (goal of n = 15-20 total)

## Methods

- We developed a semi-structured interview guide based on ethnographic observational work in a laboratory working on BBVP, and review of relevant literature.
- We conducted interviews with researchers (n = 7) and undertook preliminary examination of the data using thematic content analysis[3].

## Preliminary Analysis

### What are the short- and long-term goals of your research?

- Short-term goals largely revolved around mechanistic understanding of relevant aspects of the visual system and phosphene dynamics.
- Long-term goal of the research was described as providing an analogue of normal vision, with some variation in terms of framing.

*"We are not expecting that we will recreate natural vision, but that we will create a somewhat crude approximation to it." (RI-1)*

*"The long term goal is to cure blindness in patients." (RI-3)*

### What risk-benefit ratio do you think is needed to appropriately perform BBVP research in human subjects?

- Some researchers suggested that considerable benefit was necessary to justify the risks, such as "pretty good" visual experience and "very high" benefit.
- Others described the difficulty of assessing the benefits due to the novelty of the technology, sometimes emphasizing risk reduction instead.

*"[T]o justify opening somebody's skull and putting in permanently indwelling electrodes and forcing them to deal with daily or with frequent charging of devices, devices that may generate long-term infections and so forth, the reward has to be very high." (RI-1)*

*"I think a lot of the risk-benefit ratio, what will be worthwhile for someone, is so up in the air and has to be researched to really figure that out." (RI-5)*

## Preliminary Analysis (continued)

### What level of functional improvement constitutes success in this research? Do individual success and success of the research enterprise as a whole require different definitions?

- Researchers largely agreed that success in this research involves a level of vision useful for daily activities.
- Some mentioned specific examples of such activities, while others deferred instead to end-users' own expectations and goals.

*"[S]uccess in an individual level will be, for me personally, will be when we have the ability to have somebody walk around without a white cane, not need to use blind-specific devices, on-arm devices. Will be able to read somebody's face." (RI-1)*

*"I think as an individual or as an individual patient, if the device meets the expectations, satisfies their needs, then it's a success, right? I think that's the way we thought about providing the care and the rehabilitation. We just wanted to achieve their goals." (RI-4)*

*"I think you need some form vision, to recognize some forms, and some enhancement in the ability to navigate. Those are the two things people look for." (RI-7)*

- Researchers were split, however, on whether individual success and success of the research enterprise as a whole require different definitions.

*"[T]he notion of success for the individual might diverge from the notion of success for their research group, especially at the early stages." (RI-2)*

*"That's different, they're very different, I assume. If I was blind, I'd be like-- my success would be to be restored back to whatever I had. But vision prostheses right now, it's not great. It's not too great. So their expectations are different..." (RI-3)*

- Nonetheless, they largely endorsed the idea that there was an important connection between the two due to centrality of end-user preferences.

*"[I]f we have success at the individual level, we will have success at the field level as a whole." (RI-1)*

*"I think that the field would have a different definition, but it'd be based off of still success from individuals, even though some individuals may not have the same beneficial advantages, if that makes sense." (RI-5)*

## Next Steps

- Conduct and analyze **additional researcher interviews** (total projected n = 15-20)
- Examine the resulting full dataset **on these and further issues** (e.g., anticipated device impacts on agency and quality of life, post-trial access, perceived public attitudes, enhancement potential and acceptability)
- Interview **recipients of BBVPs** (projected n = 5-12)

## References

- Lane FJ, et al. Ethical Considerations in the Development of Neural Prostheses. In *Neurobionics: The Biomedical Engineering of Neural Prostheses*. John Wiley & Sons, Ltd; 2016:294-318.
- van Velthoven E A M, et al. Ethical implications of visual neuroprostheses—a systematic review. *J Neural Eng*. 2022;19(2):026055.
- Boyatzis, R. E. 1998. *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications.

### Are BBVPs best described as restoring previous vision, or as generating a new kind of vision?

- There was general agreement among these researchers that BBVPs generate a novel form of vision, as opposed to being best conceptualized as restoring previous vision, though with one researcher characterizing the issue as merely "semantics" (RI-7).

*"[I]t's pretty widely conceptualized in the field as very distinct from natural vision. And we wouldn't even say that we try to restore partial vision, restore it partially, or anything like that. It's just completely different, and that's the way we always tell people." (RI-4)*

- A few researchers, however, suggested that the concept of restoration could still be helpful for aiding public understanding and for conceptualizing the device's interactions with the brain.

*"I think that they generate new means of vision. But in essence, their success is based on the brain, uses prior knowledge, and how it is to see. So the brain learns to see using the same primitives in the end. So it's different means shifting back to a partial old vision." (RI-2)*

*"I think that generating a new kind of vision is definitely more accurate and descriptive. But I think that restoring vision makes sense and is easier for people to grasp and understand." (RI-5)*

### What impact (if any) does blindness have on potential participants' identity?

#### How has research participation impacted this?

- Some researchers emphasized that blindness has a notable impact on identity and related constructs, as well as that the details of this phenomenon and how BBVPs might impact such domains are best addressed by blind individuals themselves.

*"I think it has a big impact on their identity. I think it is a constant factor in their lives, never-ending, unremitting." (RI-7)*

*"[L]oss of vision in many ways defines people's relationships with other people. And so the idea that you might give them back or restore part of that lost function may change how they identify in society and how they identify themselves." (RI-8)*

*"I have encountered that [in] various papers, but surprisingly not from the standpoint of being blind. I don't know if it happens, but maybe that would be a nice opportunity to have the blind community explain it. But they say that the transition, the adaptation, either to becoming blind or to having their sight restored... influences and destroys their previous sense of being themselves. But it's a very subjective experience, and I think that the only place we can draw data from is the blind community." (RI-2)*

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