Neurotechnology industry partnerships and patient experiences: Findings from interviews with neurotechnology researchers

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Background

Partnerships between industry and academic medicine are critical for developing and advancing innovative neurotechnologies to treat patients.

These partnerships raise ethical concerns that have tangible implications for patient experiences, well-being, and outcomes resulting from neurotechnology research and clinical treatments.

Methodology

In-depth interviews of 30 Neurotech researchers:
14 Industry relationship (IR)
16 No industry relationship (NIR)

We report on themes from qualitative analysis focused on patient experiences.

Responsibility to patients — 40% of participants

"...the two depression trials...were halted because of futility analysis, How do you continue to fund these trials?...How do you ultimately help these patients who are very sick and identify those that are going to benefit the most from this potential treatment?" (IR.002)

"The problem with the private industry is that those companies can fold or be absorbed, or products can be discontinued. Then people who are dependent upon these devices can no longer use them." (NIR.009)

Patient safety and pain management — 26.7% of participants

"We had a patient...he was on hold with the company when his battery ran out for something like three days or something. When the battery runs out, this is a pain patient, so he went from zero pain to excruciating pain. Then they put him on a...hold line for hours. That's crazy." (NIR.008)

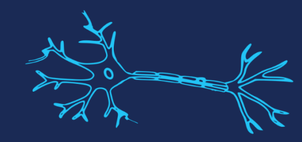
"...pain's tough because from my understanding with people with chronic pain is that they'll do almost anything to have the pain go away. If that requires you to have a paddle in place implanted into your spinal cord or to have stimulators around your dorsal root ganglion, they'll do it." (IR.008)

Inconvenience and cost to patients — 20% of participants

"On [the patients'] end, we keep hearing, "How much is it gonna be? Is it gonna be more than what I currently pay?...I wish I could have it, but if it means that it's gonna cost this much, I won't get it. I'm sorry." That's one of the major things we hear." (NIR.014)

"Futility analyses...indicating that a trial shouldn't continue, and it being discontinued after being advertised to potential participants, or discontinued safely, of course, but discontinued while participants are still receiving the intervention, things like that. I think the locus of control is outside of the Institution, and outside of the investigator." (NIR.015)

Patient privacy — 16.7% of participants



"If you have brain imaging...it takes a long process to deidentify [brain data], and sometimes we don't know what may be identifiable." (NIR.011)

"...because the rules and regulations, the laws surrounding patient privacy are so strong, everybody seems to abide by them from my experience. I don't think that [privacy] would be a concern." (IR.007)

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