Despite increasing interest in the ethics of basic intracranial research, there is a lack of focus on two areas: patient-participant perspectives and basic intracranial research.

**METHODS**

As part of an ongoing qualitative study, semi-structured interviews were conducted with patient-participants (n=14) across two sites. The interviews were conducted by members of the team who do not conduct intracranial research. Interviews were recorded, transcribed, and coded independently by at least two team members, using a codebook developed by all team members. A grounded thematic analysis was completed to develop emerging themes.

**RESULTS: Initial Themes**

### Ease of Decision to Join

**Question Prompt:** Was the decision to join difficult?

I did not really think about that...if there was a risk, they would have stopped it or they wouldn't have done something like that. 

I didn't think about it...if they had done something like that. 

Maybe just taking on a little bit of extra risk might work, if something had gone wrong, maybe you'd feel stupid for extending the risk... 

I think the decision to join was easy for me. I was just like, yea, that's going to help someone else. Absolutely, I'll do it. 

### Minimal Concerns About Risk

**Question Prompt:** Did you have any concerns about the study for, example, related to any additional risks?

I didn't feel like it was a risk...I just felt like its going to help someone else. 

I would have been more concerned about the surgery...any surgery, you get your teeth pulled, potential problems, but no, it just never occurred to me that there would be any concerns at all. 

### Unlimited Understanding of Study Goal

**Question Prompt:** What did you take the purpose of the research study to be?

I don't know the purpose of the study really, like what they're expecting to find, or if they're hoping to find, I don't know how it will affect the surgery...but that's ok. 

I don't know what the heck I've contributed to it, but I feel good about it. Okay? There's not a whole lot of information out there on it, so why not...I like being a part of something obviously bigger than myself. 

### Motivations to Help Others

- I think that's why I did it. You feel good that you're able to do something that helps someone else down the line. Someone is benefitting from it. 
- I think it's important to help in the advancement of human knowledge and to support other researchers and scientists. 
- It was a good decision, since I had my open head anyway, to try and poke around inside of it and see what was going on inside of there. 
- I was grateful for the people that did anything to help so I can have the surgery, someone could practice stuff and learn stuff, so as long as you're in there you might as well go for it. 
- I don't even feel like I was really in a stress...I just felt like it was going to be a little bit of a challenge. Therefore, I did not have any decision to make. I would expect to do surgery of this type anyway. 

### Impact of Surgical Context

**COMPARATIVE RISK EVALUATION:**

- You're already going through all this risk and preparation and stress and they're going in your brain anyway. As long as you're there, if you can accomplish something helpful. 
- I would have been more concerned about the surgery...any surgery, you get your teeth pulled, potential problems, but no, it just never occurred to me that there would be any concerns at all. 
- It was a good decision, since I had my open head anyway, to try and poke around inside of it and see what was going on inside of there. 
- I was grateful for the people that did anything to help so I can have the surgery, someone could practice stuff and learn stuff, so as long as you're in there you might as well go for it. 
- I didn't even feel like I was really in a stress...I just felt like it was going to be a little bit of a challenge. Therefore, I did not have any decision to make. I would expect to do surgery of this type anyway. 

**Impact of Invasive Experiences**

- I've lost several very dear friends to Parkinson's, so anything I can do to help make people feel better and continue to live. (P8)
- I was very grateful for the people who did anything to help so I can have the surgery...someone could practice stuff and learn stuff, so as long as you're in there you might as well go for it. 

**TRUST**

- I didn't trust him then and I wouldn't have agreed to have surgery done at all. 
- I'm trusting with this and that and if this is a way that can help anybody. 
- It was an easy decision for me. I was just like, yea, that's going to help someone else. Absolutely. I'll do it. 
- I don't think there's any risk. I just fully trust him. 
- I do not think there's any risk. I just fully trust him. 
- I think it's important to help in the advancement of human knowledge and to support other researchers and scientists. 

**REFERENCES**