Recommendations for ethical implanted BCI research

13 participant-led recommendation areas

“We are not just only a participant, but we're also making the science actually happen ”
– BCI Pioneer



From access to information through post-trial care – research participants are at the center of implanted BCI research.

Access to information

01

Make trials **easy to find** and easy to evaluate

- Share trial information via rehab centres, therapists and trial registries
- Help candidates judge trial quality & connect them with peer support
- Don't withhold trial information – sharing it does not amount to endorsement

Trial eligibility

02

Decide eligibility **with people**, not about them

- Keep criteria reasonably flexible so they don't needlessly exclude
- Discuss eligibility with candidates rather than presuming
- Look for reciprocal compatibility between participant and team

Recruitment

03

Be **clear, brief, and honest** about burdens, benefits and uncertainties

- Explain purpose, burdens, timelines and uncertainty of benefit
- Be explicit about therapeutic prospects and access to a working device
- Encourage continued rehabilitation, and make alternatives known

NDAs and restrictions on data sharing

04

Participants should be **free to talk** about their experience

- NDAs should be narrow, clear, time-limited and negotiated before consent
- Include non-waivable exception for safety, rights and suspected misconduct
- No penalties for inadvertent disclosure

Confidentiality of participant information

05

Respect individual choices and make privacy promises consistent and honest

- Reconcile research confidentiality with requests to sign media releases
- Let participants choose whether to be named, and revisit it over time
- Acknowledge that absolute privacy may not be possible

Informed consent

06

Make consent an accessible, supported and **ongoing process**

- Use plain language; flag consequences that aren’t obvious; ensure people are supported through the process
- Reconfirm consent when the protocol materially changes
- A practical, no-penalty right to leave, with independent check-ins

Recognition and compensation

07

Cover expenses, compensate time and **recognize expertise**

- Pay participation costs in advance where possible
- Compensate time fairly, including events that promote the research
- Credit participants' intellectual and experiential contributions

Expectation management

08

Acknowledge uncertainty and **clarify device ownership** and control

- Make sure participants understand what study agreements say
- Communicate task and decoder changes that affect proficiency
- Clarify ownership and control of the device before implantation

Participant-researcher relationship

09

Offer research participants **a place on the research team**

- Roles can include advisor, partner or co-researcher
- Create conditions for candid communication
- Recognize and actively mitigate power asymmetries

Participant engagement

10

Offer **meaningful opportunities to contribute** that honor the purpose bringing people to trials

- Recognize curiosity and scientific contribution as motivations
- Offer meaningful involvement in trial design and team meetings
- Include enjoyable or directly useful activities where feasible

Brain data status and privacy

11

Brain data is personal information and researchers are its stewards

- Participants keep a right of access to their own data
- New uses and open-repository uploads need participant approval
- Participants choose whether to be named with their data

Post-trial care

12

Responsibility doesn't end when the trial does

- Fund device maintenance and updates for a reasonable period
- Give ample notice, and set aside escrow funds for explantation
- Plan for researcher moves; design devices for lasting basic function

Managing media and misinformation

13

Insist on **accurate portrayal**

- Accurate coverage of spinal cord injury, neurological disorders, BCIs & trials
- Realistic expectations for the public and future research participants

A living statement

Reviewed every 24 months and open to perspectives of more research participants.

Please reach out to info@bcipioneers.org to get involved.