Brain-computer interfaces research priorities survey

Introduction

Why are we asking for your help?
The James Lind Alliance (JLA) brings individuals with lived experience, carers, clinicians, and researchers together to agree the research questions that matter most. This survey is the very first step: we want to hear your unanswered questions about implanted brain-computer interfaces (BCIs) so that, later this year, all stakeholder groups can work together to rank them in order of importance.

What exactly do we mean by an implanted BCI?
Implanted Brain-Computer Interfaces are devices that interface with the central nervous system to restore lost motor and/or sensory capabilities for people living with motor impairments (e.g., limb weakness, amputation, or speech impairments).

In other words: A brain-computer interface is an implanted device that records signals from the brain or spinal cord and translates that activity into control commands for devices like smartphones, laptops, or robotic prosthetic limbs. These signals may also help to restore functions such as speech or limb movement. Some systems additionally use electrical stimulation to send signals back to the body, enabling users to experience sensations like touch or pressure.

This definition helps to limit the scope of the Priority Setting Partnership. This definition DOES NOT include deep-brain stimulation systems, epilepsy monitoring systems, or neurorehabilitative therapies that do not record and translate motor intentions.

How the survey works
1. Tell us about yourself (individual with lives experience, carer, clinician, etc.) - this helps us check we have heard from everyone.
2. Write your unanswered questions, that you think research needs to answer, in the boxes provided.
Examples: "How should clinical benefit be assessed after receiving a BCI?" OR "How long must a patient stay in hospital following BCI implantation?"
3. Submit as many separate questions as you wish. If you are unsure whether a question is “allowed”, or has already been answered by research, include it anyway. Our information specialists will check the existing evidence later.
Need some more information on BCIs first? Have a look at our short Educational Poster (click here) and come back when you're ready!
Thank you for helping to shape the future of BCI research!

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Survey Overview

Throughout this Priority Setting Partnership, we are specifically interested in considering BCI applications in stroke, spinal cord injury, and motor neuron disease. We've divided the survey into the following categories to gather your questions:

1. Eligibility and Candidate Selection
2. Surgical Procedure and Peri-Operative Care
3. Device Performance and Functions
4. User Training, Calibration, and Learning
5. Everyday Use and Quality of Life
6. Maintenance, Upgrades, or Longevity
7. Safety, Side-Effects, and Long-Term Outcomes
8. Ethics, Privacy, and Data Security
9. Access, Funding, Service Delivery
10. Regulation and Governance
11. Future Directions and Innovation
12. Anything Else

Here are some examples of questions relating to the categories above, to spark your thinking: 'Who owns the data collected by the BCI?', 'What minimum cognitive abilities should a candidate have?', 'Can a BCI help people walk again?', 'How quickly can someone be trained to use a BCI?', 'How can BCI performance be measured?', 'How many surface channels are required to enable high DOF robotic upper limb control'

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About You

1. Which best applies to you? Select all that apply.

- [ ] Person with lived experience of motor neuron disease (e.g., ALS)
- [ ] Person with lived experience of spinal cord injury
- [ ] Person with lived experience of stroke
- [ ] Caregiver - of person with motor neuron disease (e.g., ALS)
- [ ] Caregiver - of person with spinal cord injury
- [ ] Caregiver - of person with stroke
- [ ] Clinician - Neurologist
- [ ] Clinician - Neurosurgeon
- [ ] Clinician - Neurointerventionalist (Neuro IR)
- [ ] Clinician - Rehabilitation
- [ ] Speech and language therapist
- [ ] Occupational therapist
- [ ] Physiotherapist
- [ ] Researcher (e.g., neuroscientist, engineer)
- [ ] Other (please specify)

2. In which country do you live, and if applicable, work?

- ◯ Australia
- ◯ Canada
- ◯ China
- ◯ France
- ◯ Germany
- ◯ Japan
- ◯ Netherlands
- ◯ Switzerland
- ◯ United Kingdom
- ◯ United States of America
- ◯ Other (please specify)

3. How would you describe your current knowledge of brain-computer interfaces (BCIs)? Please select the statement that best applies to you.

- ◯ 1. I have never heard of brain-computer interfaces before this survey.
- ◯ 2. I have heard of BCIs but don’t know much about them.
- ◯ 3. I have read about BCIs in popular or scientific articles but lack in-depth knowledge.
- ◯ 4. I have direct or professional experience with implanted BCIs or in BCI research and development.

4. The survey will commence on the next page. We estimate the survey will take 15 minutes to complete in the absence of any motor impairment. To ensure the survey meets your needs, please select the option that best describes you:

- ◯ I require an adapted version of this survey because my condition will make it difficult to complete the full survey.
- ◯ I will be able to complete the full survey as written.

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Eligibility and Candidate Selection

5. Please add any question(s) or thought(s) you may have about who should (or should not) receive an implanted BCI. If you do not have any relevant questions or thoughts, please move to the next page.

An example of a relevant question may be: "Would individuals with cerebral palsy benefit from BCI implantation?"

Surgical Procedure & Peri-operative Care

6. Please add any question(s) or thought(s) you may have about safety, surgical approaches, anaesthesia, hospital stay, post-implantation care, discharge etc. If you do not have any relevant questions or thoughts, please move to the next page.

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Device Performance and Functions

7. Please add question(s) or thought(s) you may have about measuring device performance, device accuracy, speed, reliability, control strategies, sensory feedback etc. If you do not have any relevant questions or thoughts, please move to the next page.

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User Training, Calibration, Learning

8. Please add question(s) or thought(s) about device training, device set-up, calibration, adaptation over time etc. If you do not have any relevant questions or thoughts, please move to the next page.

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Everyday Use and Quality of Life

9. Please add question(s) or thought(s) you may have about home integration, implications for caregivers, daily set-up requirements, psychological impact etc. If you do not have any relevant questions or thoughts, please move to the next page.

Maintenance, Upgrades, and Longevity

10. Please add question(s) or thought(s) you may have about battery life, hardware replacement, software updates, durability etc. If you do not have any relevant questions or thoughts, please move to the next page.

Safety, Side-Effects, and Long-Term Outcomes

11. Please add question(s) or thought(s) you may have about infection, wound healing, side-effects, device explantation etc. If you do not have any relevant questions or thoughts, please move to the next page.

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Ethics, Privacy, and Data Security

12. Please add question(s) or thought(s) you may have about informed consent, who owns the brain recording data, autonomy, hacking risks etc. If you do not have any relevant questions or thoughts, please move to the next page.

Access, Funding and Service Delivery

13. Please add question(s) or thought(s) you may have about healthcare system provision/funding, cost-effectiveness, equity etc. If you do not have any relevant questions or thoughts, please move to the next page.

Regulation and Governance

14. Please add any question(s) or thought(s) you may have about regulatory approval processes, clinical trial design, watching for problems after approval etc. If you do not have any relevant questions or thoughts, please move to the next page.

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Future Directions and Innovation

15. Please add question(s) or thought(s) you may have about emerging materials, decoding of brain signals, robotics, integration with new devices etc. If you do not have any relevant questions or thoughts, please move to the next page.

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Final Question: Anything Else?

16. Are there any other questions that you would like to add?

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Adapted Low-Burden Survey

We've organised BCI topics into the following categories. As you write your questions and thoughts, please keep these areas in mind:

1. Eligibility and Candidate Selection (Questions about who should and should not receive a BCI)
2. Surgical Procedure and Peri-Operative Care (Questions about what happens during surgery and recovery)
3. Device Performance and Functions (Questions about how well the BCI works, what is can do, and how it is measured)
4. User Training, Calibration, and Learning (Questions about how the device is set up and how users train and adapt overtime)
5. Everyday Use and Quality of Life (Questions about what it is like to use the BCI at home on a typical day)
6. Maintenance, Upgrades, or Longevity (Questions about topics such as battery life, software updates, and receiving new devices)
7. Safety, Side-Effects, and Long-Term Outcomes (Questions about the risks, complications, and lasting effects)
8. Ethics, Privacy, and Data Security (Questions about consent, data ownership, and data protection)
9. Access, Funding, Service Delivery (Questions about cost, NHS/insurance coverage, and availability)
10. Regulation and Governance (Questions about how BCIs are approved, monitored, and regulated)
11. Future Directions and Innovation (Questions about topics such as new materials, new decoding methods, robotics)
12. Anything Else

17. Please use the space below to write any questions or comments you have about **any** of the categories listed above. Whenever you don't have any further questions or thoughts, simply continue to the next page.

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Optional Post-Survey Demographics Questions (Completely Voluntary)

The following questions allow us to gather more information about who you are, to ensure that all groups are represented.

To make sure we hear from a wide range of people, we'd like to learn a little about who you are. Your answers are anonymous and will only be used in aggregate to check that all voices are represented. You can skip and complete the survey if you'd rather not answer.

18. What is your sex?

- ◯ Male
- ◯ Female

19. What is your age?

- ◯ 18 to 24
- ◯ 25 to 34
- ◯ 35 to 44
- ◯ 45 to 54
- ◯ 55 to 64
- ◯ 65 to 74
- ◯ 75 or older

20. Which race/ethnicity best describes you? (Please choose only one.)

- ◯ Asian or Asian British
- ◯ Black, Black British, Caribbean or African
- ◯ Mixed or multiple ethnic groups
- ◯ White
- ◯ Other ethnic group (please specify)