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Understanding Patient Preferences for Implantable Brain–Computer Interfaces in Motor Neuron Disease: A Cross-Sectional Survey

J. F. M. Brannigan MA MBBChir[1]*, H. L. Horsfall MBBS MRCS[2,3,4], R. Cave RCSLT PhD[5,6], L. Bashford PhD[7], W. Muirhead MD FRCS[2,3]

1. Nuffield Department of Clinical Neurosciences, University of Oxford, Oxford, UK, 2. Department of Neurosurgery, National Hospital for Neurology and Neurosurgery, London, UK, 3. The Francis Crick Institute, London, UK, 4. UCL Hawkes Institute, University College London, London, UK, 5. Department of Computer Science, University College London, London, UK, 6. Motor Neuron Disease Association, Northampton, UK 7.Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK

*Jamie Brannigan; John Radcliffe Hospital, Headley Way, Headington, Oxford, OX3 9DU; jamie.brannigan@medsci.ox.ac.uk

Introduction: Motor neuron disease (MND), often presenting as amyotrophic lateral sclerosis (ALS), leads to profound motor and communication deficits. Implantable brain–computer interfaces (iBCIs) that decode cortical signals to drive assistive devices represent a promising avenue for restoring functional independence. However, patient preferences and tolerances regarding iBCI risks, training burdens, and desired outcomes remain incompletely understood. This cross-sectional survey sought to characterize these preferences in people with MND (pwMND) in the UK.

Material, Methods and Results: A web-based survey was disseminated by the MND Association (30 September–15 December 2024). Thirty-nine pwMND responded (32 complete responses, 7 partial), encompassing varied ages and disease severities. Most (66.7%) used digital devices hourly, although 30.8% could not operate these devices by hand and relied on assistive technologies such as eye tracking. Self-reported familiarity with BCIs was generally low, but individuals with more advanced disease tended to have slightly higher awareness.

Asked which functions they would most like an iBCI to restore, participants prioritised mobility, communication, and arm/hand control. Among digital-specific applications, communication tools, work/employment, and entertainment/leisure emerged as the top three preferences. Other activities, such as managing finances and controlling smart home environments, were also mentioned as top priorities.

Respondents were generally open to neurosurgical implantation if it led to meaningful functional benefits (80% “Agreed” or “Strongly Agreed”). However, only 60% accepted implantation if the device would remain effective for just one year. Respondents were also willing to receive a device in the context of higher surgical risk (1% risk of death), with 80% of patients again indicating they would accept implantation to restore meaningful functions.

When asked about post-implantation training, participants reported a median upper limit of 12 total sessions if they could be conducted at home, but only 5 sessions if they required travel to a clinical site. Almost half (48.5%) indicated that each session should not exceed two hours, and most participants preferred infrequent device recalibrations (ideally once every few weeks or months). These findings suggest tolerance for a training and recalibration burden lower than is required in most iBCI academic studies.

Accuracy, ease of use, and long-term reliability were top priorities when deciding whether to receive an iBCI, surpassing raw speed in importance. More than 90% wanted guarantees of ongoing technical support to minimise the risk of device abandonment.

Conclusion: This survey offers new insights into the real-world priorities of pwMND regarding surgically implanted BCIs. Whilst there is a clear willingness to accept neurosurgical risk for potentially life-enhancing gains in mobility and communication, participants desire robust device accuracy, reliable technical support, and minimal training burdens. The absence of any iBCI background knowledge indicates that patient groups may benefit from the delivery educational workshops or materials where individuals are being recruited to iBCI studies. These patient-informed preferences should help guide clinicians, researchers, and industry partners in designing and evaluating iBCIs that align with the practical realities and aspirations of individuals living with MND.

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