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Brain–computer interfaces patient preferences: a systematic review

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E-mail: Jamie.brannigan@medsci.ox.ac.uk**Keywords:** brain–computer interface, paralysis, patient preferences, neurologySupplementary material for this article is available [online](#)

Abstract

Objective. Brain–computer interfaces (BCIs) have the potential to restore motor capabilities and functional independence in individuals with motor impairments. Despite accelerating advances in the performance of implanted devices, few studies have identified patient preferences underlying device design, and each study typically captures a single aetiology of motor impairment. We aimed to characterise BCI patient preferences in a large cohort across multiple aetiologies. **Approach.** We performed a systematic review of all published studies reporting patient preferences for BCI devices, including both qualitative and quantitative data. We searched MEDLINE, Embase, and CINAHL from inception to 18 April 2023. Two reviewers independently screened articles and extracted data on demographic information, device use, invasiveness preference, device design, and functional preferences. **Main results.** From 1316 articles identified, 28 studies met inclusion criteria, capturing preferences from 1701 patients (mean age 42.1–64.3 years). The most represented conditions were amyotrophic lateral sclerosis ($n = 15$ studies, 53.6%) and spinal cord injury ($n = 13$ studies 46.4%). Individuals with motor impairments prioritised device accuracy over other design characteristics. In four studies where patients ranked performance characteristics, accuracy was ranked first each time. We found that the speed and accuracy of BCI systems in recent publications exceeds reported patient preferences, however this performance has been achieved with a level of training and setup burden that would not be tolerated by most patients. Preferences varied by disease aetiology and severity; amyotrophic lateral sclerosis patients typically prioritised communication functions, whereas spinal cord injury patients emphasised limb control and sphincteric functions. **Significance.** Our findings highlight that despite advances in BCI performance exceeding patient expectations, there remains a need to reduce training and setup burdens to enhance usability. Moreover, patient preferences differ across conditions and impairment severities, underscoring the importance of personalised BCI configurations and tailored training regimens to meet individual needs.

1. Introduction

Brain–computer interfaces (BCIs) are devices that have the potential to restore motor capabilities and functional independence in patients afflicted

by paralysis due to conditions such as stroke, spinal cord injury (SCI), and amyotrophic lateral sclerosis (ALS). BCIs function by decoding neural signals corresponding to motor intentions, which can enable the control of digital devices,

robotic prosthetic limbs, and high-speed language output [1–3].

The literature comprises a rapidly expanding number of publications relating to BCIs, however these primarily focus on device engineering, and few studies have identified patient preferences underlying device design. The consideration and integration of patient perspectives is essential for the meaningful clinical translation of BCI devices. The FDA has highlighted that patient preference work helps to ‘*find unmet patient needs, identify the most important benefits and risks of a technology, and assess patients’ views on different clinical study outcomes*’ [4]. More specifically, understanding patient preferences for BCI devices may help to ensure clinical priorities for BCI are appropriately addressed, including device design, functions, training requirements, and performance evaluation.

Previous studies have assessed patient preferences for BCI devices using surveys and focus groups [5, 6]. However, to our knowledge, no study has reviewed and synthesised the body of patient preference literature for BCI devices. As BCIs transition from the research lab to the home environment and approach clinical approval, understanding the priorities and preferences of potential BCI candidates is increasingly important. A synthesis of this evidence is also important as BCI devices are targeted towards a heterogeneous group of patients with paralysis. The umbrella term of paralysis includes neurological conditions impacting all levels of the motor system, including both central and peripheral nerve disorders. Each condition may vary by typical age of onset, specific deficits, and comorbidities, each of which may result in conflicting preferences. Recognising this, our study seeks to consolidate the existing patient preference literature in a systematic review.

2. Methods

2.1. Search strategy and eligibility criteria

This systematic review was conducted according to the Preferred Reporting Items of Systematic Reviews and Meta-analysis (PRISMA) guidelines. Review methodology was also aligned with published advice on how to perform systematic reviews of patient preferences [7]. The review was ineligible for prospective registration with PROSPERO due to the absence of a defined clinical outcome. Scoping searches were performed to assess existing literature and refine the review question. Final search strategies (supplementary data 1) were developed for three databases, MEDLINE, Embase, and CINAHL, using an iterative process. To maximise sensitivity, no automated search limits or restrictions were applied. Searches were performed using Ovid (Ovid

Table 1. Study inclusion and exclusion criteria.

Inclusion Criteria	Exclusion Criteria
Human study	Non-human study
English language	No discussion of brain–computer interface devices
Discussion of any brain–computer interface device	No patient preference information
Patient preference information, qualitative or quantitative	Letter, editorial, opinion article
	Conference abstract

Technologies, New York, USA) from inception to 18 April 2023. Screening for eligibility was performed in accordance with criteria in table 1.

For the purpose of this review, *brain computer interface* was defined as any device which records and decodes neural activity, generating digital output signals to control external devices [3]. The FDA definition of *patient preference information* was adopted, wherein this represents ‘*Qualitative or quantitative assessments of the relative desirability or acceptability to patients of specified alternatives or choices among outcomes or other attributes that differ among alternative health interventions*’ [4].

2.2. Selection process and data extraction

Title and abstract screening were completed using Rayyan (Rayyan Systems Inc., Cambridge, USA). Two clinician reviewers (J.B. and K.L.) performed screening. An initial blinded pilot screen of 100 records was completed to ensure concordance in application of inclusion and exclusion criteria. Decisions were unblinded with discussion between reviewers before proceeding. Both reviewers worked independently and were blinded to each other’s decisions until screening was complete. Articles were retrieved for full-text screening and data extraction using a piloted table (supplementary data 2). Column headings captured demographic information, current digital device use, device invasiveness preference, device design preferences, and device functional preferences. Relevant PPI data not adhering to the specific column headings were collated into an extra column labelled *Notes*. This was completed in duplicate by J.B. and K.L. Any differences were reconciled through discussion and consensus.

Study quality was appraised using the Mixed Methods Appraisal Tool [8], and no further studies were excluded following appraisal (supplementary data 3). The authors noted the absence of a standardised checklist to assess the quality of patient preference literature [7].

2.3. Data synthesis and visualisation

Due to study heterogeneity and limited preference data, a quantitative meta-analysis was not possible. A qualitative narrative synthesis was conducted using data and notes recorded by the reviewers during blinded data extraction.

3. Results

3.1. Study characteristics

In total, 28 primary studies were included in this study (figure 1) [5, 6, 9–34], and preference information was captured from 1701 patients.

Almost half of the included studies were performed in the USA ($n = 13$ studies, 46.4%). The median number of patients per study was 19, with a range of 1–780 patients. Eleven studies (39.3%) included mixed cohorts of patients with different clinical conditions. ALS was the most represented clinical condition ($n = 15$ studies, 53.6%), followed by SCI ($n = 13$ studies, 46.4%). Both conditions were reported in preference studies with a cumulative patient population of 1568 (92.2%). Mixed cohorts with missing subgroup data precluded a precise breakdown of patients across each condition. Other clinical conditions included Duchenne muscular dystrophy, spinocerebellar ataxia, stroke, limb loss, and multiple sclerosis. These conditions were reported in studies with a cumulative patient population of 368 (21.6%). The mean patient age ranged from 42.1 to 64.3. All manuscripts were published between 2002 and 2022. Where reported, speech disorders were identified in 37.6% patients, corresponding to 543 patients.

Half ($n = 14$, 50.0%) of the included studies involved cross-sectional patient surveys, comprising 1619 patients. Eight studies (28.6%, 96 patients) included qualitative interviews, two studies (7.1%, 14 patients) used mixed qualitative methods, one study (3.6%, 8 patients) was a patient focus group, one study (3.6%, 2 patients) was a questionnaire as part of an interventional study, and one study (3.6%, 1 patient) was a case report.

Only 18 (64.3%) primary studies reported data as specified by column headings in the piloted data extraction table (supplementary data 2). Data for the remaining studies was captured as *Notes* in the data extraction table. An evidence summary table of studies reporting data specified by the data extraction table is shown in table 2. The summary table of data for all included studies can be found in supplementary data 2. The most commonly reported data were patient preferences for device functional outputs ($n = 13$, 46.4%). Patient priorities for specific device design characteristics were reported in 4 studies (14.2%).

3.2. Digital device use

Six (27.3%) studies reported the proportion of patients currently using digital devices. The prevalence of digital device users varied widely between study cohorts (41%–100%), and there was no apparent association with either year of publication, or the aetiology of paralysis (supplementary figure 1).

3.3. Preferences for BCI device invasiveness

Six studies (21.4%), comprising 1129 patients, reported on patient preferences for BCI invasiveness, where invasive was understood by the reviewers to be synonymous with implantable. A greater preference for non-invasive electrodes was identified in 4 studies (66.7%), whilst preferences were equivocal in the remaining 2 studies. An additional preference for dry scalp electrodes was reported in one of these studies, and this preference was reaffirmed in two additional studies that did not investigate preferences for implantable electrodes. In one further final study of 31 patients with tetraplegia [30], 9 patients (29%) stated that they would categorically refuse implantable devices.

3.4. Preferences for device characteristics

Four (18.2%) studies reported specific patient preferences for BCI device characteristics, including maximum device setup time, maximum device training time, minimum device accuracy, and minimum device speed (table 3). Each study provided up to 7 pre-set response options, which are shown alongside median results in supplementary table 1.

In this sample of 151 patients, median patient preferences were:

- Maximum device setup time = 16–25 mins
- Maximum device training time = 6–10 sessions
- Minimum device accuracy = 80%
- Minimum device speed = 15–19CPM

Four (18.2%) studies asked patients to rank the importance of each performance characteristic (table 4). BCI device accuracy was consistently the top priority amongst 143 patients. Attributes such as simplicity of setup, system functions, and device speed ranked next in importance. A distinction in ranking emerged between patients with SCI and ALS, with the former placing greater emphasis on device speed. This might reflect differences in verbal communication capabilities, as only 2 cases (6.7%) of ‘speaking difficulties’ were reported in the SCI preference studies, with all patients able to provide verbal responses, whereas in the ALS studies, 490 individuals (53.6%) were reported to have a speech disorder. Neither ALS study identified device speed amongst the top 3 preferences.

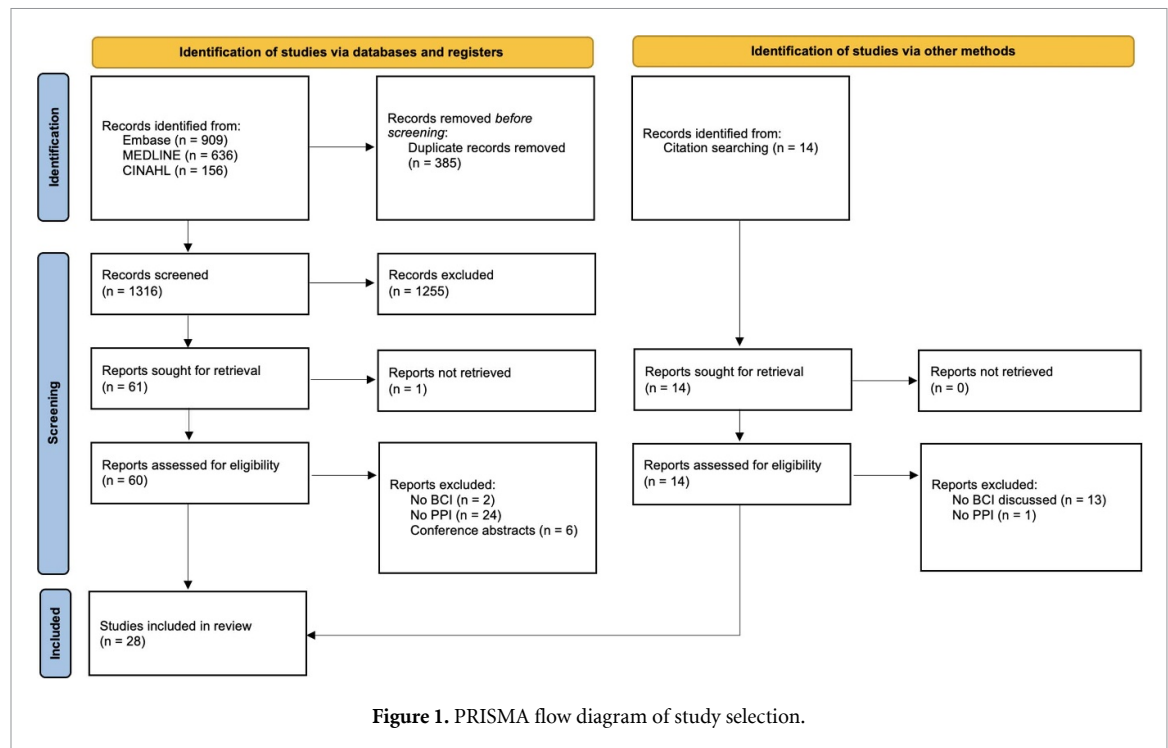


Table 2. Evidence summary of studies reporting patient preference for BCIs, organised by publication year.

Authors	Year	Country	Study Design	Number of patients	Mean Patient Age, yrs	Pathology	Data Reported
Brown-Triolo <i>et al</i>	2002	USA	Cross-sectional survey	94	NR	SCI ^c	1. Top Preferences for Device Functional Outputs
French <i>et al</i>	2010	USA	Mixed qualitative	NR	NR	SCI	1. Top Preferences for Device Functional Outputs
Sellers <i>et al</i>	2010	USA	Case report	1	51	ALS	1. Device Invasiveness Preference
Huggins <i>et al</i>	2011	USA	Cross-sectional survey	61	62 ^a	ALS	1. Top Preferences for Device Functional Outputs, 2. Current Digital Device Use, 3. Device Invasiveness Preference, 4. Preferences for Design Characteristics
Collinger <i>et al</i>	2013	USA	Qualitative interview	55	55.2 ^b	SCI	1. Top Preferences for Device Functional Outputs, 2. Device Invasiveness Preference
Zickler <i>et al</i>	2013	Germany	Cross-sectional survey	4	48.3	Mixed (ALS, stroke, DMD)	1. Current Digital Device Use
Kageyama <i>et al</i>	2014	Japan	Cross-sectional survey	77	64.3	ALS	1. Top Preferences for Device Functional Outputs, 2. Current Digital Device Use, 3. Device Invasiveness Preference
Grubler <i>et al</i>	2014	Germany	Cross-sectional survey	19	49.9	Mixed (stroke, SCI, myopathy)	1. Device Invasiveness Preference

(Continued.)

Table 2. (Continued.)

Huggins <i>et al</i>	2015	USA	Cross-sectional survey	40	52	SCI	1. Top Preferences for Device Functional Outputs, 2. Current Digital Device Use, 3. Device Invasiveness Preference, 4. Preferences for Design Characteristics
Engdahl <i>et al</i>	2015	USA	Cross-sectional survey	104	47	Upper limb loss	1. Top Preferences for Device Functional Outputs
Geronimo <i>et al</i>	2015	USA	Qualitative interview	42	59	ALS	1. Top Preferences for Device Functional Outputs, 2. Preferences for Design Characteristics
Blabe <i>et al</i>	2015	USA	Cross-sectional survey	156	NR	SCI	1. Device Invasiveness Preference
Andresen <i>et al</i>	2016	USA	Qualitative interview	5		ALS, DMD	1. Top Preferences for Device Functional Outputs
Riccio <i>et al</i>	2019	Italy	Cross-sectional survey	10	43.3	Mixed (ALS, TBI, stroke, MS)	1. Top Preferences for Device Functional Outputs
Tigra <i>et al</i>	2019	France	Cross-sectional survey	31	NR	SCI	1. Top Preferences for Device Functional Outputs, 2. Device Invasiveness Preference
Kageyama <i>et al</i>	2020	Japan	Cross-sectional survey	780	64.1	ALS	1. Top Preferences for Device Functional Outputs, 2. Current Digital Device Use, 3. Device Invasiveness Preference
Branco <i>et al</i>	2021	Netherlands	Cross-sectional survey	28	52 ^a	Locked-in Syndrome	1. Top Preferences for Device Functional Outputs, 2. Current Digital Device Use
Kim <i>et al</i>	2022	South Korea	Qualitative interview	8	42.1	SCI and DMD	1. Preferences for Design Characteristics

NR = Not reported, DMD = Duchenne muscular dystrophy, TBI = Traumatic brain injury, MS = Multiple sclerosis.

^a Median age.

^b Mean age for quadriplegic cohort.

^c Paraplegic patients only.

Table 3. Patient preferences for BCI device characteristics.

Authors	Year	Country	Number of patients	Pathology	Maximum Device Setup Time, minutes	Maximum Device Training Time, sessions	Minimum Device Accuracy	Minimum Device Speed
Huggins <i>et al</i>	2011	USA	61	ALS	21–30 ^a	2–5	90%	10–14CPM
Huggins <i>et al</i>	2015	USA	40	SCI	10–20	6–10	70%	20–24CPM
Geronimo <i>et al</i>	2015	USA	42	ALS	16–25	6–10	80%	15–19CPM
Kim <i>et al</i>	2022	South Korea	8	SCI and DMD	<15–30	1–6 months	80%	~1 min per motion ^b

CPM = Characters per minute.

^a All values are median values, unless otherwise specified.

^b Specific questions relating to BCI robotic arm control.

Table 4. Patient ranking of most important BCI design characteristic.

Authors	Year	Country	Number of patients	Pathology	Most Important Design Characteristics, median rank
Huggins <i>et al</i>	2011	USA	61	ALS	1. BCI accuracy 2. Simplicity of setup 3. System functions 4. Reliability of BCI standby mode
Zickler <i>et al</i>	2013	Germany	4	Mixed (ALS, stroke, DMD)	1. Comfort 2. Effectiveness and Speed
Huggins <i>et al</i>	2015	USA	40	SCI	1. BCI accuracy 2. BCI speed 3. System functions 4. Simplicity of setup 5. Type of electrode ^a
Geronimo <i>et al</i>	2015	USA	42	ALS	1. BCI accuracy 2. Reliability of BCI standby mode 3. System functions 4. Simplicity of setup 5. Speed

^a Preferences reported by proportion of times ranked in top 2 design characteristics.

3.5. Preferences for BCI device functions

Thirteen (46.4%) studies reported the top patient priorities for BCI device functions (table 5). From these thirteen studies, functions relating to patient communication ($n = 3$, 23.1%), locomotion ($n = 3$, 23.1%), or limb control ($n = 3$, 23.1%) were most often ranked as the top priority for restoration by BCI devices. When divided by aetiology of motor impairment, SCI patients exhibited a top preference for limb control, in the form of arm/hand function and personal grooming. In the largest study of SCI patient preferences ($n = 55$) [13], patients prioritised the restoration of autonomic functions, namely bladder and bowel function. Collinger and colleagues found that bladder/bowel function, sexual function, sensory function, and chronic pain were ranked as very important by more patients with paraplegia, while upper limb function and autonomic dysreflexia were rated as very important by more individuals with tetraplegia. Autonomic functions were reported as a top 3 priority in two further surveys of SCI patients, however they were unmentioned in other pathologies.

In ALS, patients exhibited varied preferences. Reported top preferences included locomotion ($n = 2$ studies, 103 patients), communication ($n = 1$ study, 780 patients), and entertainment ($n = 1$ study, 37 patients). Strong variation in preferences was observed between early ALS and advanced disease. Preferences for restoration of locomotion were reported in patient populations with average ALSFRS-R

of 30.3 [26] (mean) and 25 [9] (median), suggesting mild-moderate functional impairment. Top preferences relating to communication and entertainment were reported by ALS patients with average ALSFRS-R of 10 [12] (mean) and 3.1 [11] (mean), respectively. Moreover, in Kageyama's survey of 780 ALS patients [11], those with tracheostomy (57.7%, $n = 450$), and by extension more severe motor impairments, expressed significantly higher expectations for 'conversation' and 'emergency alarms' as BCI device functions than those without tracheostomy. Preference for 'essential communication support' was more highly desired than other communication functions, such as internet/email use and writing letters. Patients with more severe impairments are also more likely to use assistive communication devices, which was reported by 235 patients in this study (30.1%). Stress or trouble using such devices was reported by 200 patients of these patients (85.1%), primarily due to difficulties in immediately managing problems, updating the device, operating the display, and starting the device.

In a qualitative study of 16 ALS patients [20], questions were asked about the preferred timing of implantation of a BCI device. Patient experience of ALS ranged from <1 year to 16 years, capturing preferences from a broad range of disease progression. Overall, patients exhibited a preference for earlier device implantation in cases where disease-related functional deterioration is inevitable.

Table 5. Patient Ranking of Most Important BCI Device Functions Qualitative Interview Responses.

Authors	Year	Country	Number of patients	Pathology	Category of Top Ranked BCI Function	Preferences for BCI Device Functions
Brown-Triolo <i>et al</i>	2002	USA	94	SCI ^a	Locomotion	1. Walking 2. Standing 3. Transferring
French <i>et al</i> ,	2010	USA	NR	SCI	Limb control	1. Arm/hand function ^b 2. Bladder/bowel/sexual function
Collinger <i>et al</i> ,	2013	USA	55	SCI	Autonomic functions	1. Bladder/bowel function 2. Arm/hand function 3. Walking
Huggins <i>et al</i>	2011	USA	61	ALS	Locomotion	1. Wheelchair control 2. Robotic arm control 3. Lift control/Light control/Recline control
Kageyama <i>et al</i>	2014	Japan	77	ALS	Entertainment	1. TV control 2. Writing conversations 3. Electric bed control 4. Emergency alarm 5. Email 6. Internet use
Huggins <i>et al</i>	2015	USA	40	SCI	Home system control	1. Room temperature control 2. Computer control 3. Light control
Engdahl <i>et al</i>	2015	USA	104	Upper limb loss	Limb control	1. Open and closing hand, rotation of wrist, movement to any location, and simple grasp ^c
Geronimo <i>et al</i>	2015	USA	42	ALS	Locomotion	1. Wheelchair 2. Computer use 3. Speaker phone/TV control
Andresen <i>et al</i>	2016	USA	5	NR	Communication/Social	1. Participation with family
Tigra <i>et al</i>	2019	France	31	SCI	Limb control	1. Personal grooming 2. Food intake 3. Control of sphincters
Kageyama <i>et al</i>	2020	Japan	780	ALS	Communication/Social	1. Conversation 2. Emergency alarm 3. Changing body position
Branco <i>et al</i>	2021	Netherlands	28	Locked-in syndrome	Communication/Social	1. Direct personal communication 2. Private conversation and writing 3. General computer use

NR = Not reported.

^a Paraplegic patients only.^b Ranked preferences of quadriplegic patients.^c Questions specifically about preferences for limb control.

Patient 1. *'I definitely believe if you know you are going down that road [of needing a communication device] and it's coming, being proactive is definitely the way to go.'*

Patient 2. *'[T]here is the factor of acclimating. You know. Getting used to, getting comfortable, re-identifying yourself that now you've got this new device. It takes time. And if you wait, it is taking that much more time and it even be more difficult.'*

Patient 3. *'If you knew your timeframe was twenty years, it'd be like, 'yeah, let' do it!' But if my timeframe is 6 more months, it's like, you know, 'why bother?''*

Some studies reported how patient preferences in cases of severe paralysis differed from cases of mild paralysis. In a study of patients with paraplegia [23], those with complete paraplegia appeared to be more accepting of high-intrusive costs and interventions for obtaining walking than those with incomplete injuries. This included acceptance of a higher chance of failure, and an inpatient surgery with associated admission. Similarly, an interview study of 10 patients with mixed paralysis aetiologies revealed patients whose disability did not require permanent personal assistance tended to make negative assessments of BCI technology.

Several studies emphasised the topic of restoration of patient autonomy and independent agency as a vital aspect of any brain computer interface [19, 24, 29]. Overall, patients supported the use of a BCI if it meant a greater degree of independence from carers or family.

'Even if someone is around me 24/7, there are things that I want to do without other's help in my own space. I think BMI is a very high value technology in this respect. It is our strong desire for independent life. So, I think it can ultimately improve my quality of life.' [24]

'It's really regained independence, something has been taken away, and now you can get it back again.' [19]

'[...] it could be great for me to at least on your own environment, in your own home to be able to have more autonomy and BCI can contribute to that.' [29]

Some interviews included patients with prior experience of using non-implantable BCI devices.

These individuals reported how restoration of autonomy led to how they view themselves as people.

'Oh, God, it really changed my self-image. It changed, as I said, the empowerment. The feeling, 'I did this, look what I can do.' [29]

'I miss the training with [the robotic arm]. What I miss even more is having the job. I went to the office three days a week. I had co-workers, people I worked with and became close to. I miss the camaraderie of working with the group. I miss having a place to go and something to do every day.' [29]

4. Discussion

In this study, we conducted the first systematic review of patient preferences for BCI devices. The available evidence was limited in quantity and based on diverse patient cohorts. In studies where patients specified preferred values for performance metrics, patients' expectations for accuracy and speed appeared modest in comparison to current BCI performance benchmarks. However, patients exhibited a preference for a lower training burden than is required by most implantable BCI devices. Regarding device functionalities, preferences for communication, locomotion, and upper limb function were most prevalent, but displayed variations based on the cause and severity of motor impairment among patients.

4.1. Patients prioritise the accuracy of BCI devices

Amongst studies that assessed patient ranking of BCI performance characteristics, accuracy was consistently reported as the top patient priority [5, 9, 26]. The single exception was a survey of 4 patients, who prioritised device comfort [15]. This preference for accuracy was also reflected in the functional preferences of patients with the most severe forms of motor impairment. In ALS patients following a tracheostomy, patients exhibited a significantly greater desire for essential communication support systems, such as emergency alarms, compared to the restoration of online communication functions, such as email. Such functions require simple, dependable outputs [11].

4.2. Current performance benchmarks for speed and accuracy exceed patient preferences

Recent studies have yielded new benchmarks for the rate of language output using BCI devices [1, 35]. An electrocorticography based speech neuroprosthesis generated 78 words per minute in a person with anarthria following basilar artery stroke [1]. This corresponds to approximately 390 characters per minute, assuming 5 characters per word. Whilst this approach resulted in a median word error rate of 25%

and was limited to a 1024-word vocabulary, other approaches have generated language outputs at 90 characters per minute with no vocabulary limitations and 99% accuracy [36]. This includes implementation of a large-vocabulary language model to simulate an autocorrect feature, substantially reducing error rate.

The outputs from these studies substantially exceed median patient preferences for device speed (15–19CPM) and accuracy (80%) previously reported [5, 9, 26]. This contrast may reflect constraints imposed by the survey questions, the influence of patients' familiarity with lower output systems (i.e. extracranial BCIs), existing assistive technologies, or the obsolescence preferences due to technological advances. For example, in cross sectional surveys investigating preferred BCI speed, each question was constrained by a maximum response of 25+ characters per minute. Moreover, patients in two of these studies (66.7%) were briefed that *current BCIs used for typing one letter at a time take at about 5 letters-per-minute* [5, 9]. Both of these factors could potentially serve as anchors, influencing patient responses.

4.3. Preferences for training and setup burden remain difficult to achieve

Whilst current performance benchmarks may exceed patient preferences for device speed and accuracy, preferences for shorter training periods and faster device setup pose challenges for clinical translation. The median preferences for training and device setup time were 6–10 sessions and 16–25 min, respectively.

In recent studies of high performance implantable BCI devices, total training periods have extended over 40 h. For example, a recent study of an ECoG-based speech neuroprosthesis required 48 training sessions [37]. A similar study of an intracortical speech neuroprosthesis required 26 training sessions, lasting 2–4 h each [35]. Another study of single-character language outputs using an intracortical array required only 11 training sessions, however this followed an initial three-year period of BCI device usage after implantation [36]. While it remains unclear whether longer training times may be tolerated for higher performance, these training periods are substantially longer than reported patient preferences. This may be excessively burdensome for many BCI candidates, such as in stroke and ALS, where patients are often elderly and often suffer from moderate-severe fatigue [38, 39]. Moreover, the transport of patients with motor impairments, if required, to clinical centres for device training creates a further logistical burden for both patients and their caregivers.

Despite these challenges, a recent pre-print manuscript reports the rapid calibration of a high performance implantable speech neuroprosthesis [40]. Although this work is still awaiting peer review,

its findings may represent a breakthrough that can reduce patient burden in the coming years.

Following a successful period of training, device setup may still present an ongoing time burden. The upper limit of 25 min reported by patients for device setup may be exceeded by non-implantable and partially implantable systems, where extensive hardware setup is typically required before device use. In the case of intracortical microelectrode arrays, frequent device recalibration is also necessary, due to the inherent instability of these signals [41]. This is typically conducted under the supervision of a clinical engineer during device setup, further increasing the time and resource required. No included study reported on patient preferences for device recalibration requirements, suggesting more work is needed to better characterise preferences for BCI setup and performance.

4.4. Patient preferences vary according to aetiology and severity of motor impairment

Motor impairment is an umbrella term that comprises various pathologies affecting the brain, spinal cord, peripheral nerves, and muscles. The papers examined in this review captured responses mostly from two aetiologies of motor impairment: ALS and SCI. Preferences for desired function in ALS emphasised communication—including *Conversation*, *Writing Conversation* and *Emergency Alarm*. This likely reflects the loss of speech in ALS, and the priority to regain this function prior to limb function. These preferences overlapped with a locked-in syndrome cohort, whose top preference was to restore *Direct Personal Communication*, followed by *Private Conversation and Writing*. Exceptions were observed in two ALS cohorts, which prioritised restored locomotion [9, 26]. However, both groups reported mild-moderate average ALSFRS-R scores (25; 30.3), suggesting a retained ability to speak. Furthermore, these high ALSFRS-R scores indicate an earlier stage in the clinical progression of ALS, suggesting variation in patient preferences is more likely attributable to an individual's functional status rather than underlying disease aetiology. Mirroring the early stages of ALS, SCI patients prioritised restoration of functions relating to the limbs, such as *Arm/Hand Function*, *Personal Grooming*, and *Food Intake*. This suggests variation in patient preferences is more closely correlated with an individual's functional status rather than underlying disease aetiology. Nonetheless, disease aetiology was significant in the preference for autonomic functions in patients with SCI, namely *Bladder/bowel/sexual function* and *Control of Sphincters*, reflecting specific impairments afflicting this population.

Given these diverse preferences, future BCI devices may require bespoke configuration and training for specific patient groups. Furthermore, diverse

preferences suggest there may not be a single, universal measure of BCI outcomes. Benchmarks in the literature are classically defined by rates of language output [36, 42], however most patients with motor impairments retain the ability to verbally communicate, obviating the need for this functionality. An ideal performance metric must instead capture function in a more general manner.

4.5. Patient interviews offer further insights into BCI preferences

Qualitative interview data added a layer of nuance to quantitative preferences, revealing more detail about patient attitudes towards BCIs. In a study by Versalovic and colleagues, ALS patients articulated a tendency towards earlier BCI implantation, suggesting an inclination to proactively integrate the devices in anticipation of future impairments [20]. These discussions reveal a patient desire for preparedness in the context of progressive conditions, and they indicate it may be appropriate to align the use of BCI with individual disease trajectories.

In individuals with SCI, those with severe paraplegia demonstrated differing priorities compared to mild paraplegia. Brown-Triolo and colleagues *et al* [23] noted that patients with complete paraplegia were more amenable to higher risks and more invasive interventions if it meant the possibility of regaining ambulation. This contrasted with those who suffered incomplete injuries, who were less inclined toward high-risk interventions, suggesting that the degree of impairment influences risk tolerance and the acceptability of BCI interventions.

The qualitative data also increased our understanding of how BCIs are perceived in relation to personal autonomy. Across several studies [19, 24, 29], patients consistently identified the restoration of independence as a primary benefit of BCI technology. Specifically, the ability to perform tasks without assistance was not merely a convenience but a profound factor that ‘... can ultimately improve [one’s] quality of life’ [24].

4.6. Limitations

The available evidence was limited in quantity and based on diverse patient cohorts. Many limitations of the review arose due to inconsistencies in the reporting of qualitative and quantitative patient preferences. This diversity, reflective of the broad spectrum of disease aetiologies, severity of disease, and individual patient experiences, introduced substantial variability into the study outcomes. The heterogeneity of these cohorts makes it challenging to draw generalisable conclusions, as preferences reported may be heavily influenced by the specific demographics or disease characteristics of the participants. The populations addressed in the studies were heavily skewed

towards the United States and ALS/SCI as the predominant disease groups included. No included studies were conducted in developing countries and therefore preferences overall are reported by individuals of higher socioeconomic status, reflecting a disparity in the wider clinical literature [43]. Advanced ALS comprised the largest included population [11], meaning there was a high preponderance of significantly disabled individuals, some with tracheostomies. There was less representation from subjects with amputation, muscular dystrophy, and stroke. Study questions and discussions primarily concerned implantable BCI systems, likely due to the high risks of implantation and putative superior performance of implanted systems.

Additionally, the structuring of survey questions and the framing of response options, as observed in the largest survey studies [5, 9], potentially led to anchoring bias. In these studies, patients were informed of a contemporary performance benchmark and presented a narrow range of pre-set responses. This anchoring may have impeded the accurate interpretation of results, as it became unclear whether the responses reflect genuine patient preferences or were merely reactions to the options provided. Further quantitative studies were identified [24, 26], however a low quantity of consistent data precluded a meta-analysis.

This review highlights future opportunities to better characterise BCI patient preferences.

Inclusion of large cohorts of different patient groups in the same survey study may allow direct comparison of responses between different disease aetiologies. To reduce the risk of anchoring when assessing device performance preferences, questions in future studies should allow free text responses. Questions may also be posed using alternative modalities, such as visual demonstrations of device performance. Additional information may be captured, such as the maximum acceptable frequency of recalibration, along with preferences for different types of implantable device, device removability, and the abandonment problem [44]. Lastly, we hope to better characterise patient perception of device risks, particularly with hypotheticals; comparisons to device benefits, including a scenarios where there is no guarantee of device efficacy.

5. Conclusions

This systematic review is the first to evaluate BCI patient preferences, including device design characteristics, functionality, and corresponding patient demographics.

Patients exhibited a consensus preference for accuracy when considering the most important BCI design characteristic. Functional preferences varied depending upon both aetiology and severity of motor

impairment, with late-stage ALS and locked-in syndrome patients emphasising communication functions, and SCI patients prioritising limb function and autonomic functions. BCI speed and accuracy in recent studies may exceed median patient preferences, although a notable gap persists in aligning device performance with other patient priorities, such as minimising training and setup burden. Future work is required to better characterise patient preferences in the trade-off between device functionality and training burden, including comparisons between different features of implantable BCI devices.

Data availability statement

All data that support the findings of this study are included within the article (and any supplementary files).

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Conflict of Interests

Dr Brannigan reports consulting fees from Synchron and the UK Advanced Research and Invention Agency (ARIA). Dr Fry is an employee of Synchron and reports stock options from Synchron.

Contributors

J F M B conceived the study, conducted the systematic literature search, reviewed all titles and abstracts, selected eligible articles, extracted the data from individual articles, verified the data, interpreted the results, and drafted and co-wrote the article. K L reviewed all titles and abstracts, selected eligible articles, extracted the data from individual articles, verified the data, and co-wrote the article. H L H interpreted the results and contributed to drafting of the article. L B interpreted the results and contributed to drafting of the article. WM interpreted the results and contributed to drafting of the article. A F conceived the study, verified the data, interpreted the results, and co-wrote the article.

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