Including participants with speech and physical impairments in BCI research: Challenges and lessons learned

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INTRODUCTION

Many BCIs are designed for use by people with severe speech and physical impairments. However, including these individuals as study participants is often challenging. We present lessons learned from two recent studies of non-invasive EEG-based BCI communication systems. Recommendations for including participants with disabilities and ensuring effective and ecologically valid data collection are provided.

STUDIES

STUDY 1

- 2 participants with advanced ALS, vision impairments, and minimal volitional movement
- 5 copy-spelling sessions with SSVEP BCI in weekly visits
- Alternating-treatments single-case research design comparing:
  - Shuffle Speller with SSVEP
  - Shuffle Speller with eye tracking
  - Traditional AAC software with eye tracking
- Outcome measures: typing accuracy, typing speed, user experience (workload, comfort, satisfaction)
- Published as [1]

STUDY 2

- 12 participants with severe speech or physical impairments
  - ALS, MS, SCI, PLS, incomplete LIS (brainstem stroke), Duchenne muscular dystrophy, Friedreich's ataxia, Charcot-Marie-Tooth disease, Guillain-Barre syndrome
- 5 consecutive calibrations of the RSVP Keyboard P300-based BCI [2]
- Repeated self-ratings of sleepiness, boredom, and comfort
- Outcome measures: AUC, drowsiness detection score, self-ratings
- Unpublished data

LOW CALIBRATION ACCURACY

- 11 of 12 participants in Study 2 completed two or more calibrations (1 was unable to continue due to pain/discomfort from the cap)
- 3 had AUCs ≤ 0.70 in 5/5 calibrations
- 3 had AUCs ≤ 0.70 and ≥ 0.80 on the same day
- Differences between highest and lowest scores measured up to 0.22

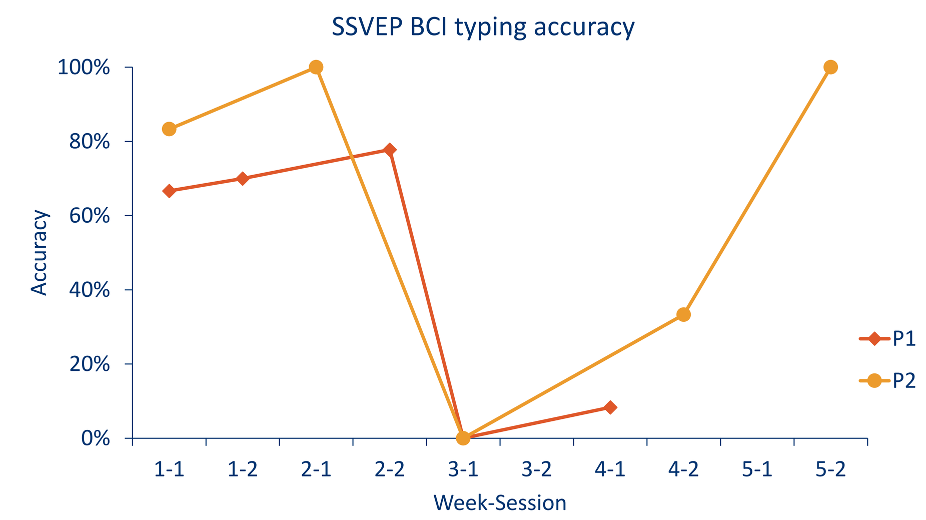
ID	Diagnosis	Session 1	Session 2	Session 3	Session 4	Session 5
1	LIS (brainstem stroke)	0.71	0.59	0.81	0.73	0.75
2	Duchenne MD	0.85	0.93			
3	ALS	0.67	0.61	0.66	0.67	0.65
4	ALS	0.93	0.88	0.86	0.89	0.82
6	MS	0.55	0.62	0.59	0.47	0.50
7	SCI	0.81	0.73			
8	SCI	0.77	0.69	0.80	0.78	0.67
9	MS	0.83	0.83	0.85	0.74	0.87
10	Charcot-Marie-Tooth	0.92	0.92	0.82		
11	Guillain-Barre	0.85	0.79	0.74	0.64	0.78
12	PLS	0.57	0.60	0.58	0.51	0.54

LESSON LEARNED

- Performance may be consistently low for some participants with disabilities, but variable for others, even within sessions on the same day

VARIABLE TYPING PERFORMANCE

- Both participants in Study 1 had variable typing accuracies across weekly visits



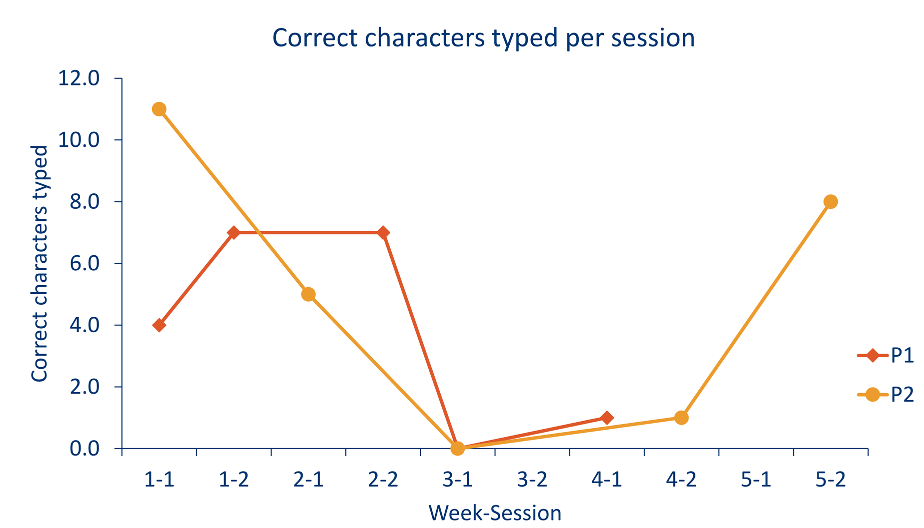
- 2/5 sessions with accuracy ≤ 33.3%
- Maximum accuracies of 88% and 100%
- Performance likely affected by illness or fatigue

LESSON LEARNED

- Poor performance on a single day may not indicate inability to use BCI

UNSUITABLE PERFORMANCE MEASURES

- In Study 1, Shuffle Speller required a variable number of queries for character selection



- Participants made 3 to 12 total selections in sessions of the same duration
- Higher accuracy did not always lead to a larger number of correctly typed characters

LESSON LEARNED

- Accuracy (%) may not be a suitable DV when query length is variable

DIFFICULTY COLLECTING DATA ON SUBJECTIVE MEASURES

- In Study 1, administration of an adapted 17-item user feedback questionnaire [3] was planned for each typing session
- Participants responded using small chin or eye movements, which were increasingly difficult, effortful, and time-consuming
- With participants' approval, the questionnaire was shortened to 5 items for one and discontinued entirely for the other

LESSON LEARNED

- Participants can provide feedback with yes/no responses and partner-assisted scanning
- Even adapted questionnaires may be prohibitively difficult for some participants with severe impairments

How much *physical* effort or activity was required to operate the system?

7	Extremely high
6	Considerably high
5	Somewhat high
4	Neither high nor low
3	Somewhat low
2	Considerably low
1	Extremely low

REFERENCES

[1] Peters B, Bedrick S, Dudy S, Higger M, Kinsella M, McLaughlin D, Memmott TR, Oken B, Quivira F, Spaulding S, Erdogmus D. SSVEP BCI and eye tracking use by individuals with late-stage ALS and visual impairments. *Frontiers in Human Neuroscience*. 2020;14:457.

[2] Oken BS, Orhan U, Roark B, Erdogmus D, Fowler A, Mooney A, Peters B, Miller M, Fried-Oken MB. Brain–computer interface with language model–electroencephalography fusion for locked-in syndrome. *Neurorehabilitation and neural repair*. 2014 May;28(4):387-94.

[3] Peters B, Mooney A, Oken B, Fried-Oken M. Soliciting BCI user experience feedback from people with severe speech and physical impairments. *Brain-Computer Interfaces*. 2016 Jan 2;3(1):47-58.

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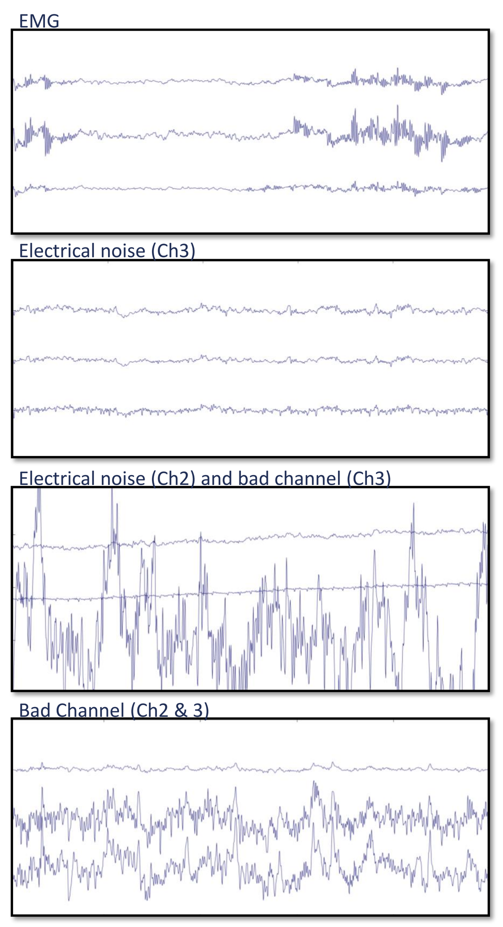
POOR DATA QUALITY

- In both studies, data were collected in participants' homes
- Data were visually inspected for quality prior to recording, and during recording for Study 2
- Post-experiment offline review revealed significant artifacts (examples at right) that rendered several sessions unusable for planned analyses



LESSON LEARNED

- Online signal viewing is vital to real-time artifact identification and minimization for increasing the reliability of field data
- Robust artifact handling is needed to minimize impacts of noise on typing performance

HARDWARE-RELATED DISCOMFORT

- Study 2 data were collected with a 24-channel dry electrode cap
- One participant was unable to begin data collection, and three more ended data collection early (after 2-3 calibrations) due to discomfort
- Participants reported headache, neck pain, trigeminal nerve pain, and general discomfort after even short periods of use

LESSON LEARNED

- Dry electrode caps may cause pain or discomfort for users with complex medical conditions and/or impaired mobility, especially for long periods of use

RECOMMENDATIONS

- Consider study designs with multiple data collection sessions per participant, such as single-case designs [4], to capture within-participant performance variability and observe potential learning effects
- Ensure that dependent variables adequately measure performance under experimental conditions
- Minimize the effort required for participants to provide UX feedback
- Use online signal viewing to facilitate real-time artifact identification and minimization
- Consult electrode cap manufacturers for advice on optimizing user comfort and signal quality
- Ask frequent yes/no questions about pain or discomfort when working with participants with communication impairments, and watch for signs of discomfort such as changes in facial expression

SIGNIFICANCE

These recommendations may support the effective inclusion of people with SSPI in BCI research, which is crucial to the development of BCI systems that work for their intended populations.

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