



# Perspectives of Persons with ALS on the Design of Brain-Computer Interface (BCI) Communication Technology

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## ABSTRACT

Brain-computer interfaces (BCIs) may serve as augmentative communication systems for individuals with amyotrophic lateral sclerosis (ALS) who have lost the ability to speak and move their limbs. While BCI technology has potential value for these individuals, BCI research has emphasized issues such as algorithm development and signal processing techniques instead of BCI user needs and preferences.

In this study, an in-depth qualitative focus group was conducted with eight dyads of potential BCI users -- individuals with ALS and their caregivers. The participants were asked about their needs and preferences when considering the possibility of using BCIs as a future communication technology.

Participants expressed concern about personal factors that would affect their ability to effectively use a BCI such as fatigue, comfort, set-up convenience, technical expertise, and appearance. In addition, relational factors that would impact the ability of the BCI to facilitate interpersonal communication garnered considerable attention. These included issues such as flexibility of the communication interface, the ability to communicate remotely, and the simultaneous benefit and burden of the technology on relationships with family and friends. Participants were eager for research to address these concerns, expressing that a functional communication network would reduce feelings of isolation, increase independence, and improve their quality of life.

Focus group findings can better direct practical research by aligning BCI technologies with user needs and preferences and systematically integrating their opinions into the design and development of acceptable communication technology.

## FOCUS GROUP METHODOLOGY

Focus group participants were recruited from a sample of persons with ALS who had previously used a P300-based BCI speller with a visual display as part of a separate research study. Caregivers of these individuals had either observed the BCI research protocol or had a chance to view the set-up and operation of a P300-based BCI speller immediately prior to the focus group. The P300-based BCI works as follows:

- An electroencephalogram (EEG) cap is placed on participant's head
- Gel creates an electrical connection between the EEG cap and scalp
- 6x6 grid of letters and commands is presented on a computer screen
- Rows and columns of the grid flash in a random manner
- Participants count the flashes of the desired letter or command
- The BCI selects the letter/command and presents it on the screen

A focus group was conducted with both persons with ALS and their caregivers. While all participants responded independently without the use of assistive technology, occasionally caregivers would assist in clarifying what a person with ALS had said. Permission to engage in human subject research was obtained from the University of Michigan Institutional Review Board and written informed consent was obtained from all members prior to the focus group beginning.

The focus group protocol consisted of open-ended questions about participants' initial impressions of the BCI, positive and negative features, personal priorities for BCI function and design, and ways this technology might impact the lives of persons with ALS and their caregivers. The focus group transcript and resulting themes were analyzed with NVivo 7 software.

## ACKNOWLEDGEMENT

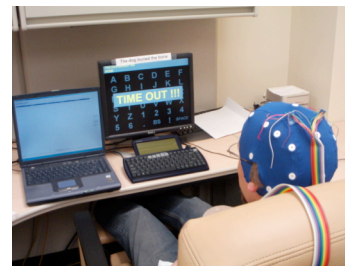
This research was supported by funding from the National Institute on Disability and Rehabilitation Research (H133G090005)



## FOCUS GROUP PARTICIPANTS

Table 1: Characteristics of Focus Group Participants

Participant ID	Age	Gender	Experience with BCI Testing	Relationship to Participant w/ALS
I1	56	M	3 sessions	N/A
I2	62	F	3 sessions	N/A
I3	58	M	3 sessions	N/A
I4	56	M	3 sessions	N/A
I5	62	M	3 sessions	N/A
I6	64	F	2 sessions	N/A
I7	78	F	3 sessions	N/A
I8	78	M	3 sessions	N/A
C1	54	F	Observed	Wife of I1
C2	64	M	Observed	Husband of I2
C3	65	F	Observed	Wife of I3
C4a	65	F	Observed	Wife of I4
C4b	30	M	Observed	Son of I4
C6a	64	F	Observed	Sister-in-law of I6
C6b	64	F	Observed	Friend of I6
C7	73	M	Observed	Husband of I7
C8	48	F	Observed	Daughter of I8



## FOCUS GROUP THEMES AND REPRESENTATIVE QUOTES

Category	Issue	Number of Dyads	Representative Quote
<b>Personal Factors Associated with BCI User Preferences</b>			
Physiological	Physical fatigue and endurance	4	"I found that after two hours, it was really tiring and I was done in." (I4)
Psychological	Cognitive fatigue	4	"... I don't know, I just wonder what my stamina would be ... I personally wonder how long I'd be able to do that ..." (I5)
Psychological	Anxiety	3	"I had a concern because of the lights and the flashing, my anxiety level seemed to be picking up toward the end." (I5)
Psychological	Attitude to technology	6	"I'm daunted by the process, and very, very concerned about my own ability to trash the whole thing ..." (C4a)
Psychological	Managing distractions	5	"... all of a sudden the ice cube maker, you know, drops ice cubes. Your train of thought gets staggered ..." (C8)
Physical	Pain and discomfort	3	"All three times, she said her cap, by the time she was done doing the session, she had a slight headache ..." (C6b)
<b>Relational Factors Associated with BCI User Preferences</b>			
Corporal	Electrode type	6	"Whether it's the cap or a hat or something you put on, to me, the end results would have to justify whatever the means were." (I1)
Technological	Relationship between BCI and other hardware	5	"And when we're watching our DVR -- all the great programs that we've recorded through the week -- if he could fast-forward and I wouldn't have to do that, that would be a help." (C1)
Technological	Relationship between BCI and other software	6	"I think you need to go for shortcuts ... maybe 10 phrases -- I'd like to see you; 'I need help with this;' ... one picture indicator that we had to focus on rather than spell out ..." (I4)
Social	Relationship between person w/ALS-caregiver	8	"It can alleviate concerns that you have; it could give you, the caregiver, more time to maybe take care of things that you need done." (C1)
Social	Training and support personnel	3	"A helpline -- you could call and diagnose what you think the issue is and ... hopefully they could walk you through some possible options ..." (I1)
Social	Appearance	5	"... It would be a small price to pay for all of us to ... be completely shaven in order to have electrodes attached ... and the women can wear wigs." (I4)