

SPECIAL COMMUNICATION

Brain-Computer Interface Users Speak Up: The Virtual Users' Forum at the 2013 International Brain-Computer Interface Meeting



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Abstract

More than 300 researchers gathered at the 2013 International Brain-Computer Interface (BCI) Meeting to discuss current practice and future goals for BCI research and development. The authors organized the Virtual Users' Forum at the meeting to provide the BCI community with feedback from users. We report on the Virtual Users' Forum, including initial results from ongoing research being conducted by 2 BCI groups. Online surveys and in-person interviews were used to solicit feedback from people with disabilities who are expert and novice BCI users. For the Virtual Users' Forum, their responses were organized into 4 major themes: current (non-BCI) communication methods, experiences with BCI research, challenges of current BCIs, and future BCI developments. Two authors with severe disabilities gave presentations during the Virtual Users' Forum, and their comments are integrated with the other results. While participants' hopes for BCIs of the future remain high, their comments about available systems mirror those made by consumers about conventional assistive technology. They reflect concerns about reliability (eg, typing accuracy/speed), utility (eg, applications and the desire for real-time interactions), ease of use (eg, portability and system setup), and support (eg, technical support and caregiver training). People with disabilities, as target users of BCI systems, can provide valuable feedback and input on the development of BCI as an assistive technology. To this end, participatory action research should be considered as a valuable methodology for future BCI research.

Archives of Physical Medicine and Rehabilitation 2015;96(3 Suppl 1):S33-37

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Brain-computer interface (BCI) systems interpret brain activity directly, enabling communication and control by individuals with minimal or no reliable motor function.¹ The field of BCI research has made great strides in recent decades and continues to hold significant promise for clinical rehabilitation. At this point, it may

be wise for the community of BCI developers, prescribing clinicians, users, and funders to ask questions such as the following: (1) Where are we going? (2) How can we ensure reliable, safe clinical implementation for the people who need BCI? and (3) What principles will guide the future development of the field? As an assistive technology interface, BCI can provide an access option for people with severe speech and physical impairments that preclude the use of other interfaces.² When used for communication, BCI systems can be considered an innovative augmentative and alternative communication (AAC) device. BCI may benefit people with impairments related to stroke, spinal cord injury, neurodevelopmental disorders such as spinal muscular atrophy or cerebral palsy, and neurodegenerative diseases such as amyotrophic lateral sclerosis.² Historically, BCI development has

Presented to the National Institutes of Health, National Science Foundation, and other organizations (for a full list, see <http://bcimeeting.org/2013/sponsors.html>), June 3-7, 2013, Asilomar Conference Grounds, Pacific Grove, CA.

Supported in part by the National Institutes of Health (grant nos. 1R01DC009834, R13DC012744, EB00856) and the U.S. Department of Education (National Institute on Disability and Rehabilitation Research) (grant no. H133G090005). Any opinions, findings, conclusions or recommendations expressed in this publication are those of the authors and do not necessarily reflect the views of the funding agencies.

Disclosures: none.

occurred in research laboratories with engineering teams, with little input from potential users. As BCIs are implemented with target users in their homes, we must consider the principles of participatory action research (PAR) and user-centered design, incorporating users' expertise, needs, and daily challenges into design decisions and clinical practice.³⁻⁵ PAR emphasizes a sharing of power between researchers and those being researched, so that they become equal partners in the research process. Rather than passive "subjects," PAR involves active "participants" who influence the future of the investigations to which they contribute.³ For BCI, this means that potential users can play an important role in the design, development, refinement, and implementation of BCI-based assistive technologies. People with disabilities should provide input that influences relevant clinical implementation, so that clinicians and families see its potential impact on participation in daily life.⁶⁻¹¹

The International BCI Meeting, held every 3 years, provides an opportunity for BCI researchers from around the world to meet and share ideas. Although 315 people from 29 countries registered for the 2013 meeting,¹² only 1 person with severe disabilities was physically present, providing a stark illustration of the need for user input in the BCI field. To ensure that the voices of potential BCI users would be heard by this diverse and important group of researchers, the authors organized the Virtual Users' Forum. The forum was held in conjunction with the awards ceremony during an unopposed time slot on the final night of the meeting, and all meeting attendees were invited. It included a presentation of results from surveys and interviews with BCI study participants, and 2 authors who are also BCI users gave live speeches on their own views about BCI. Gregory Bieker presented in person with the help of a paid caregiver, who read his prepared remarks. Catherine Wolf, PhD, participated in the forum from her home via a Google+ hangout (an internet-based virtual meeting allowing 2-way transmission of both audio and video). With this technology, she could see and hear the other presenters and the audience, and address them using text-to-speech software on her home computer.

Here we present a report on the Virtual Users' Forum, with the goal of sharing some initial comments from BCI users and drawing attention to the importance of PAR in the continued growth of the field. We report not on a fully realized study, but on preliminary results of ongoing efforts to gather and incorporate user feedback into BCI research, with a goal of encouraging widespread use of PAR in all BCI efforts.

Methods

Data presented during the Virtual Users' Forum came from 3 sources: (1) responses to an online survey of expert BCI users; (2) transcripts of interviews with novice BCI users; and (3) prepared statements from 2 authors who are also BCI users. All participants had severe disabilities and experience with 1 of 2 different noninvasive BCI systems: the Wadsworth BCI Home System (BCI24/7) and the RSVP Keyboard. Both systems use wet-

electrode electroencephalography signals acquired via a cap studded with electrodes, which are filled with conductive gel before each use to ensure a good connection with the scalp. The 2 systems also share a common control signal, the P300 event-related potential. The P300 response is elicited by a rare stimulus in a series of stimuli and has long been used as a BCI control signal.¹³ BCI24/7 presents up to 72 items in an 8-by-9 matrix.^{13,14} Caregivers are trained to don and doff electrode caps and start the system. Over repeated independent home trials, users become experts in using BCI24/7 for various applications including word processing, with word prediction and both text and speech output; e-mail; limited Internet access; games; and audio and video content such as audio books, YouTube videos, and digital photo albums.¹⁴⁻¹⁶ The RSVP Keyboard uses a rapid serial visual presentation (RSVP) paradigm, displaying a series of individual letters in the center of the screen, and features an integrated language model to improve typing accuracy.¹⁷⁻¹⁹ It is being tested by novice users in their homes during supervised research visits, with researchers setting up the cap and system.²⁰ The experiences of these expert and novice BCI users with 2 very different systems can provide valuable insight and perspectives into the range of needs and goals of target BCI-user populations.

Survey and interview data presented during the Virtual Users' Forum arose from qualitative research being conducted in connection with ongoing BCI studies at the Program for Translational Neurological Research (PTNR), a partnership between the Wadsworth Center and Helen Hayes Hospital, and Oregon Health & Science University (OHSU).

PTNR participants were involved in a study of independent home use of BCI24/7 and were considered expert BCI users. They were asked to complete an anonymous online survey created using LimeSurvey, a free, open-source survey tool. PTNR staff e-mailed or called BCI home users with information about participating in the survey. Participants completed the survey either by independently accessing the web link on a computer with alternative access, or with caregiver assistance, providing short answers and ratings on a 7-point Likert scale. Some survey questions were supplied by BCI Meeting registrants, who were notified of the Virtual Users' Forum by e-mail in advance of the meeting and asked to submit suggestions. Other questions were added by PTNR researchers. The survey included questions about research participation (eg, "Why did you try the BCI?" "What are BCI researchers doing right?"), experiences with home use of BCI (eg, "What do you use [the BCI] for?" "Did your caregiver find the BCI easy to use?"), and future directions (eg, "How would you improve the BCI?" "Would you consider getting a brain implant to run a BCI?"). Respondents could choose to skip questions, and 1 respondent completed only the first half of the survey. Therefore, some survey results refer only to the subset of respondents who answered a particular question.

Participants at OHSU had limited experience with the RSVP Keyboard during supervised in-home trials and were considered novice BCI users. They were interviewed as part of a study on patient-centered outcomes for BCI. Interviews were structured and included both general questions about quality of life and the effects of communication (eg, "Think back to when you had a good day. What made it a good day?" "How does your communication strategy affect whether you have a good or bad day?") and specific questions related to BCI (eg, "Thinking about who you are and how you live, what should a BCI communication system be able to do for you?"). Participants were interviewed in their homes, using their typical communication methods.

List of abbreviations:

AAC	augmentative and alternative communication
BCI	brain-computer interface
OHSU	Oregon Health & Science University
PAR	participatory action research
PTNR	Program for Translational Neurological Research
RSVP	rapid serial visual presentation

Two authors with severe disabilities provided the third data source, formal written comments, which they presented during the Virtual Users' Forum, as described above. Mr. Bieker is a long-time research team member for the RSVP Keyboard project who attends regular team meetings and participates in numerous ongoing studies following a PAR approach. He was among those interviewed by OHSU researchers, and both his interview responses and Virtual Users' Forum comments are included in the results. He had used the RSVP Keyboard 12 times over 3 years as part of the iterative design process and research of OHSU, always with the support and supervision of researchers, and was considered a novice user of the RSVP Keyboard. Dr. Wolf participates in PTNR research as a system tester and user interface expert, and had approximately 175 sessions with BCI24/7 over the course of 7 years. She was considered an expert user of BCI24/7 but did not complete the PTNR survey. Both Mr. Bieker and Dr. Wolf used BCI during participation in research studies rather than as an everyday means of communication or computer control.

The 8 OHSU interviewees (6 men, 2 women) ranged in age from 28 to 66 years and included 4 people with amyotrophic lateral sclerosis and 1 each with brainstem stroke, cerebral palsy, spinocerebellar ataxia, and Duchenne muscular dystrophy. All had severe speech or physical impairments, or both. PTNR survey respondents included 9 people with severe disabilities related to amyotrophic lateral sclerosis (8 men, 1 woman), ranging in age from 30 to 76 years. Five completed the entire survey or skipped 3 questions or fewer, 1 completed half of the survey, and 3 started the online survey process but did not answer any questions. Data were collected from the 6 respondents who answered at least half of the survey questions. Both the PTNR and OHSU studies were approved by the institutional review board at their respective institutions, and all participants provided informed consent.

The authors reviewed survey responses and interview transcripts to identify trends and common themes for the Virtual Users' Forum presentation. Survey questions were used as the organizing framework to identify 4 major themes across the data sources: current (non-BCI) communication methods, experiences with BCI research, challenges of current BCIs, and future BCI developments. Interview transcripts and authors' prepared comments were reviewed for content relevant to the survey questions, and these data were integrated with survey responses to establish common trends.

Results

Data from the 3 sources were organized into 4 major themes. Quotation marks appear around text taken directly from interview transcripts, survey responses, or the written comments prepared by the authors for the Virtual Users' Forum.

Theme 1: Current (non-BCI) communication methods

Since participants are not yet using BCI as a functional communication modality in everyday life, some questions focused on their current means of verbal interaction. Most participants (6 of 8 interviewed, 4 of 5 surveyed, and Dr. Wolf) used multiple communication methods, including speech, speech-generating devices with alternative access, communication boards, mouthing words, yes/no signals, and partner-assisted scanning. Partner-assisted scanning refers to a technique in which a communication partner recites the alphabet, watching for user responses to indicate a selection. Participants found that their AAC methods were

effective under the right circumstances but problematic in situations such as "conversation around the dinner table" and other social events. Several interview participants (4 of 8) discussed difficulties with group communication, as AAC is "unable to keep pace with the flow of ordinary conversation." They described the frustration of being unable to compose and express a message before the conversation had moved on to a new topic. This reflected the most common complaint about current systems: 6 of the 7 interview participants who use AAC mentioned slow communication speed as a problem. Communication partners' attitudes toward slow communication methods were also challenging. One interviewee wished her paid caregivers "would let me finish before they walk away." Another reported that caregivers sometimes refuse to set up his gaze-controlled speech-generating device because it is too time-consuming. Users of partner-assisted scanning commented that it requires patience and practice, and is subject to error. By nature, this AAC method requires the user to be dependent on another person for communication in all situations, which can be frustrating and can limit communicative participation. One interviewee who was using a speech-generating device independently after years of relying primarily on partner-assisted scanning said, "Since [getting the device] I can speak up for myself." However, Mr. Bieker, a long-term partner-assisted scanning user, preferred it over speech-generating devices, which he felt deprived him of close personal interactions with communication partners.

Theme 2: Experiences with BCI research

Survey respondents were asked about their reasons for trying BCI and their experiences as research participants. The range of responses indicated that participants appreciated the opportunity for involvement in BCI research. Four of 6 wished to explore BCI for possible future use, or because they already had difficulty with other AAC methods. Others participated in research out of curiosity or a desire to help others. Mr. Bieker joined the RSVP Keyboard project to "keep my brain active." Survey respondents were generally pleased with their experiences (when asked, "In your opinion, what are BCI researchers doing wrong?," 4 of 5 replied, "Nothing.") and appreciated researchers' patience, perseverance, encouragement, and technical support. Respondents' suggestions for researchers included making more home visits, "listen[ing] to feedback from actual users," and considering individuals' abilities and preferences when designing and testing BCIs. Finally, Dr. Wolf urged BCI testing with the target population, because healthy users may perform better than people with disabilities.

Theme 3: Challenges of current BCIs

Questions about challenges associated with current BCI systems were included in both the survey and interviews, with the goal of providing user-centered guidance to engineering teams for BCI technical development and design. Many participants (3 of 4 survey respondents and 6 of 8 interviewees) were concerned with slow BCI typing speed, anticipating problems similar to those encountered with other AAC methods. The mess, inconvenience, and discomfort of wet electrodes were another common worry, especially for novice users; this was mentioned by 2 of 5 survey respondents and 5 of 8 interviewees. Other concerns expressed by 1 or more interview participants included typing accuracy, system portability, reliability and dependability, and "using [BCI] with confidence" in a variety of settings. Some participants (2 of 5

survey respondents and 6 of 8 interviewees) worried that system setup was too complicated, time-consuming, and training-intensive for caregivers, especially with frequent staff turnover. As 1 interviewee pointed out, “cost is a major obstacle” for users who cannot afford out-of-pocket costs or insurance copayments. When asked about the ease of use of BCI24/7, all survey respondents chose moderate answers of either 3 or 5 (3 respondents each) on a 7-point scale ranging from “very easy” to “very hard.” Interviewees were not specifically asked about ease of use, since the RSVP Keyboard is not yet available for independent home use.

Theme 4: Future BCI developments

In addition to discussion of current BCI challenges, participants were asked to propose suggestions for future modifications and improvements. As discussed above, communication speed was a major concern. Two interview participants hoped for BCIs that could keep pace with natural speech: “Holding a normal conversation would be ideal.” Eventually, BCI should “translate my internal language” into speech, but also provide user controls to prevent unintentional expression of private thoughts. Three interviewees suggested that until real-time BCI speech synthesis is possible, developers should explore rate enhancement features found in current speech-generating devices, such as word and phrase prediction. Speed is not everything, however; Dr. Wolf pointed out that BCI is prone to errors, and felt that “accuracy is more important than speed,” since error correction is time-consuming.

Both interview participants and survey respondents described a need for BCI systems with a variety of applications, including face-to-face communication, writing (eg, letters, journaling, creative writing), Internet access (including e-mail and social networking), e-books, streaming video, environmental controls, telephone access, and call bells. Dr. Wolf stated a preference for using BCI with standard computer applications rather than “special BCI applications,” and a need for mouse emulation. Interview respondents uniformly said BCIs should be “simpler and easier,” and 2 recommended the use of customizable settings to suit individuals’ needs and interests (eg, display settings for users with visual impairments or specialized language models incorporating vocabulary related to the user’s vocation or hobby). Interviewees felt that setup should require minimal time and caregiver expertise (6 of 8), and live 24/7 tech support should be available (2 of 8). Four of 8 interviewees mentioned the importance of BCI-related training for users, communication partners, and caregivers. Training topics might include use and setup of BCI equipment and software, the importance of AAC (including BCI) for people with communication impairments, and how to be a good communication partner for a BCI user.

Many interviewees mentioned that future BCIs should avoid electrode gel, with either dry electrodes or invasive signal acquisition. As 1 man said, noninvasive BCIs should use “a stand-alone [wireless] cap that does not require gel.” Survey respondents had mixed feelings about invasive BCIs. One would consider a “brain implant”; 4 would not, and another would do so “only if [the] benefits are significant and [the] implant is low risk.” Interviewees were not asked about invasive BCIs, but 2 of the 8 spontaneously suggested this option when asked about how BCI could be improved, saying they would prefer an implant over the gel, “hairnet electrodes,” and complicated setup of wet-electrode electroencephalography.

Discussion

Comments from the Virtual Users’ Forum at the 2013 BCI Meeting provide insight into the opinions and preferences of potential BCI users, and offer a glimpse of how PAR may be implemented in the BCI community. The overall objective of clinical BCIs, which is consonant with general assistive technology principles, is to provide options for enhancing communication and computer control so that individuals with disabilities can function at their fullest potential for health, education, social interaction, and employment.²¹ The feedback provided here by BCI experts and novices is similar to that from people who use other AAC systems: we need to improve rate and fluency, simplify operations, and find a means to provide competent communicators with access methods so they can participate as independently as possible.^{8,22} As with all assistive technology, training is essential for end users, communication partners, and caregivers alike. Some particularly important challenges for BCI-based AAC include complicated setup requirements (eg, wet electrodes or systems with multiple hardware components); reliability, dependability, and accuracy (typically more problematic for BCI than other access methods because of the noise associated with brain signal acquisition^{23,24}); and the availability of specialized technical support services. Despite these challenges, BCI also presents unique opportunities for improving the options available to people who use AAC. Current BCI systems may provide a communication access method for individuals whose needs are not met by other options. Our participants, and others who use AAC,⁸ hope for a BCI that can “translate internal language” into speech in real time, and this wish may one day be realized.^{25,26} For BCIs to meet the demands of consumers, they must be useful, simple to operate, need minimal expert oversight, and provide reliable, long-term performance in complex home environments. By definition, such user-centered design can be achieved only by soliciting and acting on feedback from BCI users.

We have presented preliminary results from ongoing qualitative studies at 2 different BCI research centers. As part of a PAR model, the feedback we obtain through these methods will guide the iterative development processes for our BCI systems, suggesting areas for improvement and innovation, as well as considerations for future implementation in the home environment. PAR is essential to ensuring that BCI technology develops in ways that will meet the needs and expectations of users. If we do not listen to the voices of these individuals as we create the technology, then BCI clinical implementation is unlikely to achieve therapeutic goals that will improve communication and quality of life, and technology abandonment may be high. The Virtual Users’ Forum represents the growing acknowledgment among BCI researchers of the importance of user input, and more comprehensive reports of user involvement can be expected in the future.

Online surveys and structured, in-person interviews worked well for collecting feedback from BCI users, and each method has its own advantages and drawbacks. The survey provided a quick, easy way to get answers to specific questions on topics such as ease of use, overall satisfaction, and desired system features. However, use of the Likert scale and short-answer formats placed limits on the depth and range of responses, and may have denied the opportunity to address topics of interest to the respondent. Interviews with open-ended questions gave participants the freedom to discuss any topic and elicited more comprehensive feedback but were more time-consuming and labor-intensive for both participants and researchers. In other studies, additional methodologies such as questionnaires and rating scales,

telephone surveys, and focus groups have also proven useful for soliciting the opinions of potential BCI users.^{6,7,11,27} As demonstrated by Dr. Wolf's participation in the Virtual Users' Forum, Internet-based social media and communication services such as Google+ hangouts and Skype, as well as e-mail and instant messaging, can enable the inclusion of people with disabilities in PAR even when face-to-face meetings are inconvenient or impossible. The variety of methods and modalities available for soliciting feedback and involvement from potential users makes PAR a realistic goal for all BCI research and development activities.

Conclusions

Individuals with disabilities can be important partners in the effective translation of BCI technology. Using reports from people with disabilities about their BCI use at all stages of expertise should foster a more realistic understanding of the state of the technology. Their input about device satisfaction and desired outcomes can suggest research questions, guide system development, and aid in the design of appropriate clinical implementation services and outcomes measures for BCI in the home environment. Potential BCI users want their voices to be heard, and researchers should make an effort to implement the PAR model in the continued development of this technology. Such feedback should inform future translational work and ultimately bring more useful products to the people BCIs are intended to serve.

Keywords

Brain-computer interfaces; Communication aids for disabled; Outcome assessment (health care); Rehabilitation

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