

**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.

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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.<sup>1</sup> 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.<sup>2</sup> 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.<sup>2</sup> Historically, BCI development has

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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.<sup>3-5</sup> 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.<sup>3</sup> 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.<sup>6-11</sup>

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,<sup>12</sup> 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.<sup>13</sup> BCI24/7 presents up to 72 items in an 8-by-9 matrix.<sup>13,14</sup> 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.<sup>14-16</sup> 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.<sup>17-19</sup> It is being tested by novice users in their homes during supervised research visits, with researchers setting up the cap and system.<sup>20</sup> 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                |

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