

NIDCD Applied Research Supplement for Patient Centered Outcomes

Submitted by Melanie Fried-Oken, Ph.D. (PI, 5R01DC009834)

April 2, 2012

The goal of this supplement is to generate patient-centered outcomes research domains for brain-computer interface (BCI) technologies from stakeholders so that an outcomes research family of tools is ready to use when BCI intervention studies become feasible. Four steps are proposed: (1) to conduct guided interviews with three groups of stakeholders, including 8 patients with functional locked-in syndrome who are currently testing a new BCI technology, their paid professional caregivers and their unpaid caregivers (family and friends); (2) to identify their patient-centered outcome domains through qualitative analysis; (3) to map these new patient-centered domains onto already existing A.T. outcomes tools; and (4) to propose design for an accessible survey instrument that includes questions that emphasize these new and important stakeholder domains. The parent grant, whose overall goal is to develop and test the RSVP Keyboard™, a brain-computer interface with optimized language functions for people who are functionally locked-in, currently began year 4 of our 5-year funding cycle. User-centered design is an integral part of the research to date, with input from people who are functionally locked-in during all stages of BCI development. Participants attend monthly team meetings and yearly external advisory board meetings and provide input into design, measurement and functionality of the RSVP Keyboard™. Additionally, a user questionnaire that obtains satisfaction factors intrinsic to BCI for workload, ease of use, and comfort is presented to participants during BCI use in their homes. The proposed patient-centered outcomes research further extends the original user input and satisfaction data. The result of this one-year supplement will be a valid agenda for patient-centered outcomes tools to match to the field's PCOR needs. As assistive technology research and development progresses with BCI intervention studies, there will be tools ready for data collection in patient-centered outcomes. The project brings together the parent grant team of clinical scientists, engineers and computer scientists with public health professionals in epidemiology and health services research to expand the assessment of BCI impact and utilization.