When and how to address ethical issues in BCI: A qualitative study of BCI researcher and end user perspectives

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Introduction: It is widely accepted that successful translation of BCI applications depends on identifying and integrating the needs of potential end users into device design, and studies have reported BCI researchers' perspectives on ethical issues [8] and real or potential end users' priorities in device development [1-7]. Yet few have investigated these groups together to determine end users' feelings about how ethical issues ought to be addressed and researchers' perceptions of barriers to incorporating end users' perspectives outside "user-centered design." To fill this gap, we interviewed 15 BCI investigators within an NSF-funded Engineering Research Center (ERC) and conducted three (3) focus groups with potential end users of BCI technology to compare different BCI stakeholders' understanding of how ethical issues in research ought to be addressed.

Methods: Semi-structured interviews with investigators (n=15) were conducted in person or by phone. Verbal consent was obtained and all interviews were audio recorded. The investigator interview guide focused on interviewees' experience with and attitudes towards end user involvement and perception of ethical issues in research. Three moderated focus groups were conducted (n=17) with potential end users of BCI devices who self-identified as having motor disabilities due to spinal cord injury or stroke. The end user interview guide concentrated on end users' feelings about how ethical issues such as privacy and responsibility should be addressed. Pairs of researchers coded the transcribed data using grounded theory to identify themes [9].

Results: BCI researchers and potential BCI end users with motor disabilities agreed on risks and benefits of BCI devices for mobility, including concerns about surgical risks, privacy and security, and responsibility. Of most interest were areas on which they diverged: BCI researchers often assumed that ethical issues would be addressed further along the translational pathway; some said they were "not my job." By contrast, potential end users expected researchers to be responsible for addressing ethical issues throughout the design process. There was also divergence on particular ethical issues, such as methods for addressing privacy and security concerns.

Discussion: Our findings suggest that BCI researchers and potential end users share many of the same ethical concerns regarding BCI research, but that potential end users – perhaps because they consider the technologies from their situations as people living with motor disabilities – expect ethical issues to be addressed differently from BCI researchers. That is, people with motor disabilities thought that ethical issues should be addressed early and often with the public, while researchers tended to place conversations about ethical issues further along the translational pathway and expect that ethicists or other intermediaries would guide these discussions.

Significance: Beyond issues of usability, potential end users have deep concerns about individual privacy and equality of access that ought to be addressed in research along with technical design issues. Incorporating end users' perspectives on these broader issues is an ethical requirement of responsible neural engineering research.

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