

# BCI Research And User Involvement: The Role Of Independent AT Centres In The TOBI Project

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The TOBI project<sup>1</sup> aims at developing brain computer interface (BCI) controlled applications in the Assistive Technology (AT) and Rehabilitation Technology fields that are functional, reliable and evaluated positively by end users (people with disabilities and patients in rehabilitation). Although BCI technology is developing rapidly, this is a challenging task because not many research centres have tested applications with significant numbers of end users outside labs or clinics.

In their contribution to the workshop, the authors focused on the role of the two independent AT centres involved in the project and their approach to user collaboration in the development of applications for communication, environmental control and entertainment.<sup>2</sup>

The involvement of users in other TOBI application fields such as orthosis for people with spinal cord injuries and post-stroke rehabilitation, remain outside of the scope of this paper.

This paper will describe some of the characteristics of the AT centres and discuss how these features have impacted on the contribution they have made to the project as it has developed thus far. Both centres are fully integrated members of the consortium and play a notable role in WP “User evaluation”, but the project is only in its second year which means that what is presented here has to be read as *work in progress*.

The NPISH AIAS Bologna is an organisation of people with disabilities and their carers which has a 30 year history in AT service delivery. Its AT team operates an independent and public AT resource centre in Bologna (IT). The BUK centre for AAC forms part of the large Kreuznacher Diakonie care institute in Bad Kreuznach (D). Both centres advise and support people with disabilities and are engaged in identifying and personalising appropriate AT based assistive solutions. To this end they employ multidisciplinary teams composed of professionals with backgrounds in education, health and ICT/AT. Their work can involve intervention in the domestic environment or in clinics in case of particularly severe pathologies. The aim of intervention is to enable people to increase their levels of participation and to improve their quality of life. Technology is thus regarded as constituting an environmental factor with an important social impact and not merely as a collection of medical devices. The relationship between Centre clients and the assessment team may be long term with the latter intervening, upon request, at different moments in order to support the technological needs of the person as they develop over time in different areas of autonomy and life. The centres have displays of a wide range of AT devices for communication, pc access and environmental control and adhere to a non commercial ethos with regard to the AT device market. This means that different solutions can be tried and tested in a context of complete transparency concerning prices and funding, after which the person and his/her carers can make a fully informed choice.

In accordance with the project's objectives, the two centres have sought to move away from a "medical" approach that distinguishes between "healthy" and "unhealthy" subjects to a "psycho-social" approach - inspired by the ICF model - that distinguishes between "researchers", "professional users" and "potential end users, beneficiaries or clients". *Professional users* in this case are AT experts at AT centres who have a comprehensive view of user needs and available solutions and who see themselves as working together with clients in order to help them improve their lives through the adoption of assistive technologies. *Potential end users* are people with functional limitations who are seeking enabling solutions for their activities and participation. Models such as the Matching Person and Technology model<sup>3</sup> are built on this collaborative approach and provide the instruments necessary for the identification of tools and solutions that are perceived as really useful. The evaluative process in the TOBI project reflects this model: professional users and people with disabilities collaborate in providing feedback to the researchers so as to ensure the development of new assistive technologies that are perceived as useful. "End users" are both "potential users of BCI technology" and subsequently "future clients" once these technologies are available on the market.

The AT centres have emphasised how important it is that they be involved at an early stage in the testing of applications with end users. In order to enhance the project's potential in terms of technological transfer it was felt that research in the BCI field should draw on AT concepts, skills and competences as early as possible rather than develop prototypes far from the real life situations of potential users. Thanks to their experience, their technological resources in terms of alternative technologies, their possession of the necessary infrastructure - such as smart homes - and their established relationships with potential users of BCI technology, AT centres have much to contribute.

Regarding the selection of the potential end users of these new technologies, the centres have recommended moving away, at this early stage, from those groups that are typically considered potential BCI beneficiaries, for example people with Locked-in syndrome and ALS patients for whom the BCI could provide the only possible means of communication. Although it remains a long term aim of the project to provide these groups with functional solutions, it was felt that for many reasons of an *ethical, political* and *practical* nature it would be better to privilege experienced AT users with severe motor disabilities but at least one other communication channel (body signal) in more stable physical conditions.

The *ethical reasons* here concern the management of expectations and frustration, including the emotional stress that could arise from the product not being immediately available in case of positive results, as well as other considerations such as lack of choice and lack of balance in the relationship of power between the researcher and the patient.

The *political reasons* concern the difficulty of creating the conditions for an early and full involvement of these groups in all phases and aspects of the project. Such involvement is necessary in order to make the design process as user driven as possible and requires users who are fully aware and able to choose, consent, agree or disagree.

The *practical reasons* involved concern the need to reduce disturbance arising from those non BCI related factors that often characterise hospitals or other institutional care settings (noise, the presence of non relevant people, prevalence of a medical approach, shortage of time, life support equipment, etc.).

A survey of potential BCI users was conducted during the first year of the project in order to determine their satisfaction with the AT solutions they were currently using and what they would require of any new piece of technology.<sup>4</sup> The findings were too numerous to report here, but three significant outcomes are worth summarising:

Most participants were satisfied with their current AT solutions, although participants using communication devices were less so than those using other devices such as those for the enhancement of daily life activities, environmental control, computer access or mobility. Furthermore, participants using communications aids were significantly more likely to indicate a need for improvement in “decision making about own situation” and “relationship with family/friends/caregivers”.

Considering the adoption of new AT solutions, participants rated “functionality” as the most important aspect followed by “possibility of independent use” and “ease of use”. These results were underlined by the reasons given by the participants for their dissatisfaction with their current AT solutions which concerned functionality/effectiveness and ease of use.

The survey also asked participants whether they were interested in further participation in the project. A selection was made of those who responded in affirmative as possible candidates for the testing of prototypes.

Payment (or reimbursement if preferred) and employment on a contractual basis are envisaged in order to encourage the involvement of potential BCI technology users at the AT centres. Those selected are expected to participate individually in test sessions and in focus groups, discussions and presentations. User participation is designed in accordance with the Living Lab model. Living Labs are “permanent” communities of users who are involved on an interactive basis in product innovation at various stages in the design/development/validation and marketing process. Their feedback is collected by means of various socio-ethnographic research methods (focus groups, surveys, testing, polls, etc.).<sup>5</sup>

The features of Living Labs are:

- different stakeholders working together for innovation;
- an open innovation concept: sharing and spreading;
- a real life testing environment: seamless and spontaneous interaction between people and technologies (+ environments);
- a user centric approach to innovation: people’s feedback is put at the core, especially at the beginning.

The Living Labs concept is particularly appropriate to AT centres, which, to a certain extent, can be considered permanent Living Labs in AT for inclusion and participation - especially where more established and formalised relationships between clients and AT have been developed. Involvement in the TOBI project has thus turned out to be a learning process for all.

A wide range of internationally validated scales have been selected to measure different parameters. Following the classification of AT device outcomes proposed by the Consortium for Assistive Technology Outcomes Research (CATOR), these refer to the outcome areas “effectiveness”, “social significance” and “subjective wellbeing”.<sup>6</sup> They include different scales that measure subjective workload and user satisfaction, such as the NASA TXL<sup>7</sup>, the MPT – “Assistive Technology Device Predisposition Assessment” (ATD PA, both consumer and AT expert form)<sup>8</sup>, the Tübingen User Evaluation of BCI use Satisfaction (TUEBS 1.0.), which is an extended version of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST 2.0)<sup>9</sup>, the “Assessment of Life Habits” (LIFE-H)<sup>10</sup>, a well validated questionnaire that measures the social participation of persons with disabilities i.e. the performance of daily activities and engagement in social roles.

In addition to these validated scales the AT centres use focus group techniques, case histories and interviews to collect feedback from the participants. These techniques offer more opportunities to interpret the input of BCI users and to collect information on the expected benefits of BCI compared to other technologies.

The first users were selected in July 2010, put under contract and introduced to the project. They have started using BCIs and are enjoying an experience that they feel concerns their own future and that of future generations.

## References

<sup>1</sup> [www.tobi-project.org](http://www.tobi-project.org) for more information

<sup>2</sup> Independent AT centres are described by Hoogerwerf EJ, Lysley A., Clarke M and others in the multilingual project deliverable: "BRIDGE Assistive technology against social exclusion". Retrievable from [www.at4inclusion.org/bridge](http://www.at4inclusion.org/bridge).

<sup>3</sup> Scherer MJ, Craddock G. "Matching Person & Technology (MPT) assessment process". In: *Technology and Disability* Vol. 14 (3/2002). IOS Press.

<sup>4</sup> The outcomes of this survey have been reported in Zickler C, Di Donna V, Kaiser V, Al-Khodairy A, Kleih S, Kübler A, Malavasi M, Mattia D, Mongardi S, Neuper C, Rohm M, Rupp R, Staiger-Sälzer P, Hoogerwerf EJ. "Brain Computer Interaction Applications for People with Disabilities: Defining User Needs and User Requirements". In: Emiliani PL, Burzagli L, Como A, Gabbanini F, and Salminen AL (eds.). "Assistive Technology from Adapted Equipment to Inclusive Environments". AAATE 2009, Volume 25 Assistive Technology Research Series. Amsterdam, IOS Press, p. 185-189.

<sup>5</sup> Study on the potential of the Living Labs approach, including its relation to experimental facilities for future Internet related technologies. A study by ALTEC on behalf of the EC DG information, Society and Media. Directorate F "Emerging Technologies and Infrastructures. March 2009.

[http://ec.europa.eu/information\\_society/activities/livinglabs/docs/study/study\\_final\\_%20report\\_d4\\_1\\_e1.pdf](http://ec.europa.eu/information_society/activities/livinglabs/docs/study/study_final_%20report_d4_1_e1.pdf)

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<sup>7</sup> Hart S. & Staveland L. "Development of NASA-TLX (Task Load Index): Results of Empirical and Theoretical Research". In P. Hancock & N. Meshkati (eds.), *Human Mental Workload*, North-Holland, pp.139–83. 1988

<sup>8</sup> Scherer MJ. "Matching Person & Technology (MPT) model manual." Webster, NY: The Institute for Matching Person & Technology, Inc. 1998

<sup>9</sup> Demers L, Weiss-Lambrou R and Ska B. "Development of the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST)," *Assistive Technology*, vol. 8, pp. 3-13, 1996.

<sup>10</sup> Noreau L, Fougereyroullas P, Vincent C. "The LIFE-H: assessment of the quality of social participation." *Technology and Disability* 2002; vol. 14, pp. 113-118.

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