Assistive Technology Workshop summary

Introduction
In April 2015, experts in assistive technology met to discuss how to foster the development of technologies for people with ALS. The workshop was intended as a first step in the establishment of a funding program to promote that aim. Among its goals was to identify key strategic areas for future development of technologies to transform the way patients with ALS communicate and move. Presenters were asked to address the following discussion points regarding the technologies and the technological area being presented:

- What are the current gaps in your field that need to be addressed for the technology you are presenting to reach the wide audience of ALS patients?
- More broadly, what do you view as the gaps and opportunities in the field of assistive technologies for ALS patients?
- What are the chances and limitations for your technological area becoming integrated into standard care and being reimbursed by international insurance organizations?
- How cost effective is your technological area - what are the time and costs needed for development, and how accessible is the technology expected to be for patients?
- How adaptive is the technology to the changing needs of ALS patients as their disease progresses?
- How well can your technological solutions be combined with other solutions to assure a comprehensive approach to patients’ quality of life?

Overview and Definition of Terms
Assistive technology covers a wide range of devices, from manual spelling boards to implanted brain electrodes controlling a robotic prosthetic hand. The major focus of most assistive technologies in ALS are for communication, mobility, and activities of daily living. Speakers at the workshop presented systems that took advantage of advances in computing power and miniaturization in the design of electronic devices to further these goals.

Broadly speaking, an assistive electronic device converts a signal from the person with ALS into an action the person cannot otherwise perform, or perform well, without the device. Potentially useful signals include the direction of the gaze of the eye (eye-gaze tracking devices), the electrical signals from the brain (brain-computer interface, or BCI) picked up by electrodes on the scalp implanted in the brain. Other signals not discussed at the workshop include small movements of the hand or fingers, or a sip or puff through a mouthpiece. Actions may include the typing of a letter or word, turning an appliance on or off, controlling a motorized wheelchair, or moving a prosthesis.
A common type of brain-computer interface incorporates a set of non-invasive scalp electrodes to record electrical information from the brain. The signal detected is called the P300 wave. This is an “event-related potential” that is triggered by the recognition of an expected or desired stimulus, such as a letter or word. P300 is sometimes called the “aha!” wave, because it is triggered by recognition. When a PALS is presented with the choice desired (such as a word or picture on a screen), his or her brain creates the P300 wave. Detection of the P300 wave registers the choice made by the PALS, such as turning on a television or typing a common word.

Eye gaze devices reflect an infrared beam off of the user’s retina to determine the direction of the gaze. Typically, the gaze must remain focused on a point (such as a letter on a keyboard) for a certain period of time in order to register a choice of that letter.

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**Personalization of BCI in ALS**
Andrew Geronimo
Departments of Neurosurgery, Engineering Science and Mechanics, Penn State University

Dr. Geronimo is developing personalized P300-based BCI systems for communication to improve efficiency. Inefficiency stems from a variety of sources, from genetic heterogeneity to clinical state to poor electrode placement or contact. In his 2014 study, he showed that behavioral and cognitive impairments affect interest in and performance on BCI systems. In addition, repeat length of the C9orf72 gene negatively correlated with task performance. PALS could be classified into those who could and those who could not learn to use the system.

Questions and responses
4. How cost effective is your technological area- what are the time and costs needed for development, and how accessible is the technology expected to be for patients?
   • Limited commercial systems available now. Expensive (more so than eye-tracking systems) and require trained user.
   • Relatively small systems utilizing open source software can easily be adapted for home use.
   • Low cost EEG systems possible, and designed by collaborators in the CNE.

5. How well can your technological solutions be combined with other solutions to assure a comprehensive approach to patients’ quality of life?
   • Easy integration of EMG and EOG (electro-oculogram) to utilize available control modalities.

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**Eye Gaze Wheelchair and Hands-Free Keyboard**
Jay Beavers, Microsoft Research, Enable Team
The project to develop a wheelchair that can be controlled by eye gaze grew out of a 2014 Microsoft hackathon. It is now a formal research project at Microsoft, with an expanding staff. The components are cheap and off the shelf, including the eye-tracking technology for input, and an output device that feeds into the directional controller for the wheelchair (in place of a joystick). The PALS uses eye gaze to select a direction arrow on an onboard computer screen.

Questions and responses
1. What are the current gaps in your field that need to be addressed for the technology you are presenting to reach the wide audience of ALS patients?
   --Sunlight interferes with gaze tracking. Eyeglasses, especially progressive lenses, reduce tracking ability.
   --The system requires practice, and ideally should be started before it is strictly needed. (For eye-gaze technology generally, an untrained person can focus to the size of quarter, a trained person to the size of dime, and a superstar like Steve Gleason to the size of a grain of rice.)
   --Frequent recalibration is required, though this is getting better.
   --Operating system integration currently requires writing custom apps to integrate with different systems.
   --There is currently no 360° vision built into electric wheelchairs, and the patient is often laying back with a trach tube.

2. More broadly, what do you view as the gaps and opportunities in the field of assistive technologies for ALS patients?
   --Eye-gaze driven speech generation is currently slow and not personalized, with an average rate of 5 words per minute. Steve Gleason types 100 characters per minute, but this takes expertise and focus.

3. What are the chances and limitations for your technological area becoming integrated into standard care and being reimbursed by international insurance organizations?

4. How cost effective is your technological area- what are the time and costs needed for development, and how accessible is the technology expected to be for patients?
   The team is working to create a system that would cost less than $2000 for materials, which is probably 30% of total cost.

5. How adaptive is the technology to the changing needs of ALS patients as their disease progresses?
   The team is pursuing eye gaze as a technology that remains effective throughout the disease.

5. How well can your technological solutions be combined with other solutions to assure a comprehensive approach to patients' quality of life?
The Microsoft Surface is compatible with a broad selection of hardware and software choices, allowing multiple apps to interact and integrate.

Philips/Accenture ALS Proof of Concept — Connected Health
Bob Koppes, Accenture/Philips

Connected Health seeks to combine existing consumer technology to build proof-of-concept solutions to problems. A prototype device was described, developed in partnership with Philips and Emotiv, which is tablet-based. The tablet can take as input a large variety of devices, including BCI, eye gaze, EMG, voice, and touch. The tablet is used to control the output, which could be home appliances, emergency call systems, or communication devices.

The system as described is less than $1000, based on off-the-shelf hardware such as a $200 tablet, $400 headset (detecting left/right motion for choice between two options shown on the tablet). The system is easily scalable, since it uses available hardware. If the software is made open source, it can be maintained by others, and possibly by corporations interested in “good citizenship.” Connected Health did not include wheelchair applications in this version over concern for liability.

Smart glasses can display what's happening on the tablet, but they cannot yet be used for eye gaze tracking. An advantage is that they move with the head.

Reimbursement for some components is challenging: a standard TV is not labeled as an “assistive” device. Input devices are already being reimbursed.

Questions and responses
1. What are the current gaps in your field that need to be addressed for the technology you are presenting to reach the wide audience of ALS patients?
   a. “Lack” of ‘Business Case’/ funding
   b. Readiness consumer BCI Technology

2. More broadly, what do you view as the gaps and opportunities in the field of assistive technologies for ALS patients?
   a. Gaps/ opportunity: agnostic flexible solutions
   b. Opportunity: make the ‘business case’ wider than ALS

3. What are the chances and limitations for your technological area becoming integrated into standard care and being reimbursed by international insurance organizations?
   a. Connected home will be standard
   b. Reimbursement will be hard in beginning due to use of consumer technology
4. How cost effective is your technological area- what are the time and costs needed for development, and how accessible is the technology expected to be for patients?
   a. Third party consumer technology is 'cheap', scalable and sustainable
   b. If using third party connected home platform; 6 months – cost est. TBD

5. How adaptive is the technology to the changing needs of ALS patients as their disease progresses?
   a. Extremely; anything with A and B output can be added as control device

6. How well can your technological solutions be combined with other solutions to assure a comprehensive approach to patients' quality of life?
   a. Easily; but dependent on initial build

The plans for the Neurotechnology Center of the University of Pittsburgh Brain Institute
Christi L. Kolarcik, Systems Neuroscience Institute
Department of Neurobiology, University of Pittsburgh

The group is developing a respite-like home facility to let patients get used to assistive technology. They would then move back home with the technology, perhaps to return when new technology is added or for additional training. The immersion in the technology aids learning. The “heart and soul of the system” is an implanted microelectrode array, in the motor cortex, to record neural activity, which can operate devices including a prosthetic arm. The “Strong Arm” for transfers is being commercialized, with up to 250 lbs capacity. There is also currently a kitchen bot. The team expects that in 6 months or less they will have a BCI-implanted subject (spinal cord injury) in a smart apartment, and within 3 years, it should be fully wireless, and have FDA approval.

1. What are the current gaps in your field that need to be addressed for the technology you are presenting to reach the wide audience of ALS patients? More broadly, what do you view as the gaps and opportunities in the field of assistive technologies for ALS patients?
   Most significant gap: Getting developed technologies to the home environment
   Most significant opportunity: Shifting the attitude can snowball into better technologies

2. What are the chances and limitations for your technological area becoming integrated into standard care and being reimbursed by international insurance organizations?
   Decreasing caregiver burden will aid with insurance companies; advocacy for proven technology

3. How cost effective is your technological area- what are the time and costs needed for development, and how accessible is the technology expected to be for patients?
   Significant costs for development, focusing on more effective time costs
   Accessible with opportunities to improve with testing in the home-based setting
4. How adaptive is the technology to the changing needs of ALS patients as their disease progresses?
Completely adaptable once a patient learns to use a BCI

5. How well can your technological solutions be combined with other solutions to assure a comprehensive approach to patients’ quality of life?
Easily coordinated and integrated with other aspects of care

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**Non-invasive P300 brain-computer interface: success and challenges**
Eric W. Sellers, Department of Psychology, East Tennessee State University

Dr. Sellers and colleagues are developing a noninvasive BCI using the P300 wave. Eight electrodes in a head cap record scalp EEG. The signal is processed for the best combination of speed and accuracy (90% accuracy is the best trade-off, as asking for more than this slows down response). Nystagmus, focus difficulty, and diplopia all interfere with eye gaze, while the p300 doesn’t depend on eye movement. Dr. Sellers pointed out that an alternative, auditory BCI (in which choices are offered as auditory rather than visual stimuli), is extremely distracting and/or further isolating, since it interrupts social interaction.

1. What are the current gaps in your field that need to be addressed for the technology you are presenting to reach the wide audience of ALS patients? More broadly, what do you view as the gaps and opportunities in the field of assistive technologies for ALS patients?
A major gap is the need for low-cost, high quality electrodes. Dry electrodes are not as good as gel electrodes.
Development should be done in better-matched control subjects, not undergrads, since mood, motivation, depression, quality of life all influence the performance of the BCI in ways that are not well characterized. User-specific optimization can improve accuracy, bit rate, and preference.

3. How cost effective is your technological area- what are the time and costs needed for development, and how accessible is the technology expected to be for patients?
The ALS market is small, but the same devices can be used in SCI and stroke. Electrodes are $1000 per electrode, and 8 are needed.

5. How well can your technological solutions be combined with other solutions to assure a comprehensive approach to patients’ quality of life?
This system can be integrated with commercial systems, such as the Tobii dynavox (the current standard for assistive keyboards). It can be integrated with eye gaze, for increased accuracy.

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**Click2Speak, innovative, all around on-screen keyboard by Gal Sont**
Mr. Sont described Click2Speak, which uses SwiftKey software to improve eye-gaze typing speed and reduce error. It incorporates multiple languages and word prediction. It can incorporate multiple input devices, as PALS needs change. A model work station includes a Tobii eyeX keyboard, a Windows-based tablet with Click2speak installed, and a USB infrared receiver/transmitter. A YouTube video is available: https://www.youtube.com/watch?v=RcK9NK0l2Qs

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Low-Cost Biosignal Based Systems to Improve Quality of Life for ALS Patients
Kiran George, California State University, Fullerton

The team has partnered with Orange County Chapter of the ALS Association, with a goal of building low-cost bioelectrical signal-based systems for performance of basic tasks. Signals explored include EMG, EEG, and EOG (electrooculogram). In fall 2014, 12 PALS tried the basic prototypes for communication and use of a robotic arm. Lessons learned include the challenges of cognitive impairment, which decreases performance versus healthy controls, and practical problems including difficulty of placing the electrode headset on a PALS with a breathing mask.

The prototype system uses an inexpensive headset that detects an EMG signal, sent to a wireless transceiver in communication with an “arduino” output microcontroller. Additional or alternative inputs include a gyroscope to detect head movements and an EOG detector. Applications include control of the robotic arm to manipulate a water bottle, control of an electric wheelchair, or use of a communication device. The estimated cost of the electronic communication system is $150. The system requires minimal training and can be customized as the disease progresses. Challenges include that neural activity of patients can be very different from healthy controls.

Questions and responses

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Recent Work Towards High-Performance Brain-Computer Interface, the cortical control of neural prosthetics
Andrew Schwartz, University of Pittsburgh

Dr. Schwarz is developing implanted electrodes for control of high-performance neural prosthetics. The implanted device combines readings from multiple neurons in the motor cortex to develop a prediction of the intended movement. At its most sophisticated, the system controls an arm/hand with 17 degrees of freedom. Relatively little training is needed to control the system, as the software has been developed to perform the decoding of intention.

To date, 3 or 4 ALS subjects have been implanted. Niels Birbaumer in Germany is the expert in ALS BCI. Dr. Schwartz pointed out that the progressive loss of communication changes one’s
mental processes, so that it becomes more difficult to learn and change these devices. Regarding the concern that the device is placed in a degenerating motor cortex, the number of corticofugal neurons is only 20%, and most neurons in the cortex don't degenerate. There is loss of electrode fidelity over time, but some can be regained by retraining. The same principles could be used to facilitate speech, at least at the phoneme level. Work is currently being done to streamline the ungainly electrode port on the head, and to tune the algorithm.

Questions and responses

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**Improving The Frontier of Prosthetics for ALS: From Magnetics to Navigation**

Steven J. Schiff, Center for Neural Engineering, Penn State University

Dr. Schiff asked whether it was possible to meaningfully maintain a BCI in ALS into the completely locked in state, and if so, with what kind of interface. With a subdural implanted electrode, there is significant arachnoid scarring, so removing and replacing the device is a major issue. The longest implantation is 5 years at Brown University. Infections are “a disaster,” and a 4% infection rate is presumed.

An alternative is to use epidural magnetic sensors which respond to brain activity by twisting slightly, like “an array of tiny diving boards.” The next generation of such systems will combine sensing and stimulation. A MEMS-MAGSS (microelectromechanical MAGSS [acronym undefined]) system operates with a billionth of a Tesla magnetic field. Shielding and adaptive noise cancellation remain challenges.

Magnets placed in the home or outdoor environment could also be used as trajectory boundaries, with their location sensed by equipment on a wheelchair, for instance to guide along common trajectories or prevent dangerous movements. This could reduce the human computational and operational control needed, aiding mobility. The goal is to offload as many degrees of freedom as possible to smart robotics.

Questions and responses

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**Augmented Reality for Assistive Technology**

Ivo Yves Vieira, Lusospace

Lusospace has developed a system in which eye-gaze tracking is built into “virtual reality” glasses. An advantage is that head position is not an issue, since the glasses move with the head. Calibration is internal, with no external help needed. Currently the speed is about 20 letters per minute, with a goal of 40. Corrective lenses can be added. Wheelchair control could be added. The system is not currently compatible with all ventilation masks.
Questions and responses

2. What are the chances and limitations for your technological area becoming integrated into standard care and being reimbursed by international insurance organizations? For speaking the chances are very high. For accessing other applications and internet navigation, this depends of country/insurance policy.

3. How accessible is the technology expected to be for patients? First product will be launched in June/July 2015. The target price is between 3000 USD to 5000 USD.

Increase speed with innovative SW interface
Specific glasses for ALS (prevent discontinuation from EPSON glasses, allow different interpupil distances, ventilation mask compatibility, improve comfort)
Specific glasses for ALS using LISPLAY technology (added comfort with less visual impact and higher field of view)
EyeSpeak: Time and costs needed for development

4. How adaptive is the technology to the changing needs of ALS patients as their disease progresses? It can be used since the beginning (we will include voice recognition for early ALS stages)

5. How well can your technological solutions be combined with other solutions to assure a comprehensive approach to patients’ quality of life? We see eyespeak as an interface and we can connect it to any Bluetooth compatible device

AriSLA roadmap for assistive technology funding
Camilla Andreazza, Fondazione Italiana di Ricerca per la SLA

AriSLA is a nonprofit dedicated to funding ALS research. Projects are selected on the basis of scientific merit. One-year pilot grants, up to 60,000 euros, are for highly innovative exploration projects. Full grants, for up to three years and 300,000 euros, are for research with solid background and preliminary data.

Goals for investing in technology are to finance projects that address an unmet clinical need, and to ensure rapid access to the proposed technology. Two technology projects have been funded, each of which foundered from lack of a plan to turn a proof of concept into a marketable device. Problems included unclear intellectual property rights, and lack of R&D integration with industry to allow scale-up. Lessons learned include the need to get company involvement and the need for a focus on mature technologies.

Going forward, AriSLA will use results from a patient survey on unmet needs, and a technological round table that includes representatives of business and venture capital.
Additional Comments Provided

**Bob Koppes**
A great many things are happening both in the US and in the world in the field of Assistive Technologies (not specifically for the ALS patients), but that are often not visible to either the ALS patients or the ALS Association. I think the main power of necessary [Bob: please check] (either from the ALS associations’ side or another association) in this field could lie in four areas:

1. Seed new/revolutionary ideas; give funding to the most promising research (ideas) that would otherwise not get funding “due to a lack of business case”
2. Maximize research output; get the ideas/research that is currently in a “desk drawer” or inside large companies to the patients, even if there is no business case/the company is not in that business (like Accenture)
3. Coordinating these efforts globally across countries (minimize overlap)
4. Coordinating these efforts across different associations (minimize overlap; maximize input by directing funding)
5. Coordinating these efforts across companies/research institutes to maximize the potential outcome; if Microsoft and Accenture would start working together on this (like we have with Philips for example), great things could happen.

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**Karen Pearce**
A few issues sprung to mind for me, such as the need to consider what research is already underway internationally if this is possible. For instance, I have already seen an electric wheelchair powered by eye gaze — and have actually had a go. It’s certainly not easy and you need to be able to manage a switch as a safety stop mechanism. If other developers / researchers are aware of some of the current developments / pitfalls that have been encountered then functional equipment will be developed sooner. I appreciate this is to a degree a naive comment as there is the competition aspect, however my role is to think about the end user, and how quickly they can get what they need.

The amazing bci developments are exciting, and I would like this to be considered in the light of what people with ALS/MND are needing as soon as possible, so wearable technology such as Eyespeak/ smartglasses seems appropriate as a prime focus.

The need for reliable ie no need to keep calibrating, systems that are quicker than current systems minimizing fatigue are the areas I feel need to be concentrated on. These are the areas that will probably have the highest uptake, lowest training implications and biggest impact on quality of life for the pALS and also reduce carer burden. These areas are more likely to be funded through our statutory bodies, or be affordable for charities to loan if statutory bodies / insurers don’t fund.
I certainly see use for bci for acquired brain injury / spinal cord lesions and slower progressing forms of MND, my concern around implanted bci would be infection risk and respiratory compromise. Of course, further research will minimize risk and create better access.

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Christi Kolarcik

--A phased model for funding (similar to DARPA) fits nicely with the prize model used by Prize4Life. A Phase I set of proposals could be funded and then, based on results in a specified time frame, the Phase II awards invited/funded. There could even be a Phase III award for the continued support of the top 1-2 projects/groups.
--I also liked the Microsoft Hackathon that Jay presented. Perhaps there is a way to work this into the funding portfolio...possibly most appropriate for areas identified as immediate gaps.
--Progress meetings for these technology-based projects could be coordinated with the ALS Association’s Public Policy/Advocacy Meeting. With so many PALS in attendance, this could be a nice way to introduce and familiarize PALS with assistive technology. Mitigating fear/apprehension and presenting neurotechnologies as possibilities for enhancing quality of life (like a power wheelchair would) will be important moving forward.
--This presentation/showcase could serve as a launching point for retreats focused on PALS highlighting their abilities (similar to those organized by the Paralyzed Veterans of America).
--There are a range of assistive technologies to be developed further. It is important to distinguish between current gaps and long-term goals for funding (different mechanisms).
   Immediate gaps: Challenges/prizes, phased funding, team competitions
   Long-term goals: Multi-year grants, phased funding
--Getting neurotechnologies out of the laboratory and into the home is not an easy process to get funded.
--The new U funding mechanism was mentioned, so perhaps there are opportunities to partner with NIH agencies like the NINDS for “signature” projects focused on ALS.
--The construction of the home-based facility within the University of Pittsburgh Brain Institute is largely being supported by the University. For sustainability, funding mechanisms that stress utility in the home and in daily living are critical.
--It would be useful to develop a brochure for PALS on assistive technologies. This could include the various options currently available and in development potentially with a spectrum of invasiveness or time periods for acquiring different components. Throughout development of this document, we could engage organizations/investigators and obtain feedback from PALS. This may be a great exercise to identify the gaps and define priorities for funding in both the short- and long-term.
--Can we establish a broader view of technology for ALS (and beyond)?
--Could this be addressed, by a special task force designed to address Assistive Technologies in ALS?
--Could the ALS Registry be used to get feedback from PALS (and potentially the caregivers)?
--Could the ALS Association’s Centers for Excellence be a way to get patient feedback? These could also distribute the brochures once produced and an assistive technology “expert” included as part of the multidisciplinary care received at the clinics.
Collaborative efforts could be a specific focus of the funding...across Universities, across sectors, etc.

One thing mentioned during our discussion was that underdeveloped countries have PALS too. Perhaps some funding in combination with or even beyond commercialization could focus on accessibility in these locations. (This could be a good discussion for the International Alliance-comment form Lucie Bruijn)

Communication was highlighted by the PALS in attendance and should be a focus of the funding.

Steve Gleason: faster communication, wheelchair control (movement), portable (outside the home)

Eric Sellers
With regard to additional thoughts, something that Steve said seemed to resonate with me. He said his priorities are communication, mobility, and to go outside. A handful of us have moved P300-based communication from bench to bedside on a small scale. The communication is not fast, but it does work after eye tracking devices have failed. There is a good deal of basic science needed to increase the speed of the system, and a good deal of engineering to make it more user friendly. In regard to mobility, Microsoft is already on the case, and many basic scientists have a lot to contribute as well. Going outside and navigating the environment is probably a longer range project.

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Kiran George
While medical research is ongoing to find a cure for ALS, in my opinion there are two distinct directions that the ALS Association could take to improve QoL for PALS: (1) Study the feasibility and the potential for widespread adoption of partially invasive/invasive procedures that involves electrode implantations for BCI; (2) Survey and study the existing and experimental alternative communication and mobility devices/systems, its impact and effectiveness, and the potential for QoL improvement. I would consider direction (2) as a course of action that could be undertaken easily and with more immediate results as part of a wider range of solutions to improve QoL for PALS.

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Ivo Vieira

There is no study (from my knowledge) about the specific needs of pALS as a function of time/disease progression. My opinion is this should be the priority for funding. If not, you are gathering information mainly from researchers and companies which is not complete. The opinion from Gal and Steve is very helpful. However, note that Gal has a very high technology knowledge and Steve has a high capacity of buying expensive devices and receiving support from caregivers. This is why I believe an impartial study should be performed on:

- what are the limitations as a function of time/disease progression
- What is the satisfaction of pALS regarding current technologies
- What is the gap of current technologies with regard what they would like
- What are the important usability factors for pALS (speed of writing, mobility, calibration, etc)

Another point is about cost. Cost depends a lot about the scale of the product. When I launched the kickstarter project last year, it was extremely difficult to advertise the project in ALS community. This community is very fragmented and there is no database available. The cost of advertising is very high which increases a lot the final cost of the product. ALS association would help to decrease this advertising cost if a web page of all potential suppliers exists. If an adequate code of ethics is implemented for this, I think this would help.