In designing assistive communication technologies for people with ALS, it is important to consider their needs and wishes, as well as how the progression of the disease makes an impact on usability of a device. Those important lessons were conveyed by Drs. Terry Heiman-Patterson, of Drexel University College of Medicine in Philadelphia and Sarah Feldman, physical therapist on the staff of The ALS Hope Foundation in Philadelphia, in a recent webinar to applicants in the ALS Assistive Technology Challenge.

The ALS Association and Prize4Life are sponsoring the ALS Assistive Technology Challenge in order to spur development of communication technologies for people with ALS. In the first phase, entrants submitted proposals for the development of functional prototypes of novel communication systems that incorporate ease of use and adaptability to the changing needs of people living with ALS. The winning projects, announced in March 2016, each received a $50,000 grant to further the development of their prototypes. The grant recipients and further details can be found [here](#).

The grand prize will be given to the group with the most promising technology as assessed directly by people living with ALS. The Prize Phase is open to everyone regardless of participation in the First Phase, and will conclude in December with an announcement of the winner at a finale event in Dublin.

Communication is critical for all of us, especially those coping with a disease. Beyond serving the practical purposes of meeting physical needs, “communication is what allows others to know who we are,” Dr. Heiman-Patterson said. “It is part of what makes us human.” Approximately, 80-90 percent of people living with ALS will eventually lose their ability to communicate through speech.

The best communication device will need to take into consideration key aspects of ALS, she stressed. “It’s a progressive disease, so each day is a new day. This can lead to frustration, as the person loses another function. This can be overwhelming. You need to get a sense for this progression to design technologies that can be adapted as the disease progresses.”

Beyond the weakness of the disease, there is stiffness, which results in slowed movements, as well as fatigue, which is often underestimated, she said. These affect the choice of interfaces, since the effort to use a device may be challenging.
“Also, this is a family disease—everyone in the family is affected.” Caregivers are overwhelmed even without communication challenges, and the introduction of a good communication device can be dramatic. “If you design it right, and it works well, it can have a major impact,” she said. On the other hand, caregivers rarely have the skills to troubleshoot problems with devices, and thus a good device will be relatively trouble-free and have expert support readily available.

Augmented and alternative communication (AAC) is any method of communication that replaces or supplements speech for people with speech impairments, explained Dr. Feldman.

A fundamental choice in device design is how the user will select an input—the most basic part of using an AAC. Access of devices may be through either direct or indirect selection. In a direct system, the user moves to an object on a screen (word, symbol, etc.) and then touches it directly or uses a mouse or pointer to make a choice. Indirect selection is most commonly done using scanning, with a highlighted portion of the screen containing multiple choices, and the user makes a choice when the desired option is highlighted. Scanning is often done with a switch, which replaces the mouse. The switch is placed where it can be accessed most reliably. “We look at hands first, then the head, the mouth, the feet, and other sites in the body.”

Switches can be activated by direct touch, by accelerometer-sensed movement, or by breaking a beam of light. In an eyegaze system, a sensor tracks eye movement, and a choice is made either when the user dwells on the chosen object for a length of time, or when the user blinks.

Current technology includes smartphones, tablets, and computers. An advantage of smartphones is that many people are familiar with them, and thus are familiar with the idea of texting. It’s a short step from there to converting text to speech. The drawbacks of smartphones are that they don’t work in all situations, and the keyboard is small, increasing error rate.

iPads have larger keyboards, and can be activated with a switch or with voice. However, they do not take a mouse, they need add-on speakers for text-to-voice, and are not covered by insurance. Android tablets have text-to-speech apps, and can be accessed with a mouse or hands-free voice-activated controls, but there are not as many apps as for the iOS. They require an add-on speaker, there is no eyegaze system, and they are not covered by insurance. Microsoft tablets are lightweight, have many accessibility options, and have eyegaze for some models, but they take more time to set up and modify, require a speaker, and are not covered by insurance.

In general, Ms. Feldman said, “It is difficult at times to find the accessibility information for many of these devices.”

There are dedicated AAC devices as well, with their software specifically designed for this. These are covered by insurance in most cases, at least partially. They typically have multiple access methods, including touch screen, mouse, scanning with switch, and eyegaze. They can also be used for environmental control.
However, there is a steep learning curve to use them, including for the caregiver, they are expensive, and other features, such as Facebook, don’t always work seamlessly with the communication software.

For all devices, a key issue is mounting on the wheelchair, so that the user can easily access the screen. Another critically important issue is training. “There is a lot of need for education,” she said.

Outcome measures to determine the utility of the device may include a tally of speech rate, the ALS Functional Communication Scale, the Psychosocial Impact of Assistive Devices Survey, the Quebec User Evaluation of Satisfaction With Assistive Technology, and quality-of-life measures.

By working with people with ALS and their caregivers, and reviewing the literature, Dr. Feldman and Dr. Heiman-Patterson have identified some important difficulties with the use of AAC, which include:

- Lack of usability of tablet-based systems outdoors, because of sunlight;
- Hesitancy of non-caregivers to interact with the device, though iPads have eased this somewhat;
- Loss of control of eyelid function impacts eyegaze systems;
- Bifocals are problematic with eyegaze systems;
- Built-in speakers are often inadequate, requiring an add-on;
- Tracking systems require frequent recalibration;
- Repair and trouble-shooting can become a hurdle for continued use;
- When a voice cannot be personalized, it reduces attractiveness of use; and
- Inability to use a head-mounted device with a non-invasive ventilation mask.

Feldman noted that a common frustration of patients is that the devices don’t talk to each other, adding that separate control systems are needed for a power wheelchair, a communication device, and environmental controls. Prior to obtaining a device, people living with ALS would like more opportunity to try it and learn about it. Once they begin using it, they would like more follow-up education on its use, including in the home and with caregivers. Software updates are a big issue when they lead to incompatibility with other programs.

Finally, a few major themes have emerged: The device must adapt to the person as their needs and abilities change with the disease process, and the learning curve for new devices must be shallow and short. And costs need to come down.

“The discussion in the clinic about communication options needs to begin early,” Dr. Heiman-Patterson said. “Too often, the people living with ALS will put it off, and then experience a steep decline in voice function between visits.” Earlier discussion and exposure to options may improve their ability to quickly adopt a device when the time comes, she said.