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A CommunicationFIRST Webinar

# Brain to Text Technology?

# ¿Tecnología de Cerebro a Texto?

*A Conversation on Groundbreaking AAC Research*
*with Board Member Pancho Ramirez and*
*University of California San Francisco (UCSF) Neuroscientists*

## October 19, 2022

Questions & Answers


This document compiles questions submitted before and during the webinar by webinar attendees. Answers from the panelists below were provided both during the webinar and fleshed out afterward. They are organized by topic here.

## Pancho, what is it like for you to …?

### Q: Pancho, as a nonspeaker who struggles with physically initiating typed communication, [I want to know] how easy it is to access this tech?

**Pancho answered:** Unfortunately, right now, we're in the early stages yet, and I don't have any access to this technology unless I am plugged into the computer. My hope is that it will become fully accessible by everyone who needs it, without having to be connected by a cable, in a soon period of time.

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### Q: Pancho, how do you communicate in your daily life, when you are not in the lab? What kind of supports do you need?

**Pancho answered:** I use a head mouse to operate a desktop computer and communicate with everyone, write emails, watch movies, type messages, and do pretty much everything on a computer. This device is so awesome, an incredible little thing, it's called the Quha Zono. It comes in two pieces, one is the receiver, like a USB device, it connects to the computer and automatically pairs both devices. The second one, the mouse, could be on your glasses, or in a holder that goes over the head, like a headband. The UCSF researchers, from San Francisco, gave me a laser pointer, and a letter board, so I can have them in my bag all the time, and use them on the go, if I need to. I cannot do anything for myself, unfortunately. I have to have help with everything.

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### Q: Pancho, how do you feel about participating in this research?

**Pancho answered:** I am very happy to be involved in this AMAZING clinical trial. I love doing my sessions with my team. Especially since I know the benefits will not be for myself only, but for many people who, like me, cannot speak or communicate.

**Q: Hello Pancho, how do you hope the research and the vital role you have played will directly improve your future wellbeing?**

**Pancho writes:** My hope is that in the near future, this technology will be available to use and **I**, and every person unable to speak, will be able to speak and communicate with anyone, without a problem.

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**Q: Pancho, are your expectations from the implant being realized?**

**Pancho answered:** Not yet, but I'm hopeful they will soon!

## How does this technology work?

### Q: How does it work? It is so wonderful. Thank you!

**The UCSF team writes:** Yes, of course! Pancho has a port on the top of his head which connects to an electrode grid which rests over the surface of his brain. The grid is about the size of a credit card and has 128 recording electrodes. The grid covers the speech motor cortex, meaning the area of his brain that controls his mouth, vocal folds, lips, tongue, [and other parts of the body that are used to produce speech sounds]. During recording sessions, we put together tasks which prompt Pancho to attempt to speak. We use the neural data collected, run it through our large computer, and output the most likely output (words, letters or movements). This approach requires Pancho to repeat each word several times to allow our computers to recognize and distinguish them from each other. Pancho does an amazing job!

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### Q: How easy is the interface to position/setup by carers?

**The UCSF team answered:** Great question! In the context of our clinical trial, the device is set up by the research team. As there is a percutaneous port which must be connected to our computer, it is not easy to get set up. However, in the future, we hope to improve the device to allow for participants to use the device at home autonomously.

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### Q: Does BCI meet Pancho's bilingual needs yet, or is this in progress?

**The UCSF team answered:** This is certainly a work in progress! However, one interesting thing with our approach is that we do believe it should work in any language, as we are utilizing motor signals to decode speech. What we mean by this is that when you speak Spanish or English (in Pancho's case), you are moving your mouth, tongue, and vocal folds in complex ways to produce sounds we know as speech. These movements are common across spoken languages and thus should be able to be decoded with our approach. However, of course, this is still a work in progress and we hope to report on this soon!

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## Q: In terms of fatigue, how does this method compare with infrared eye tracking?

**The UCSF team answered:** Our goal is silent speech control that does not require any vocal output by the user, and it will also not require the user to attend to a screen during use. However, as Pancho has described during many research sessions, this method does require some focus and attention. As Pancho cannot use this system in his day-to-day life, he cannot compare how fatiguing its use is in comparison to other methods.

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## Q: How similar is this to CART (Computer-Aided Real Time Transcription) and text to speech?

**The UCSF team answered:** Thanks for your question, Avery! To my understanding, CART is live closed captioning and text to speech uses speech-generating technology. Our technology uses implanted electrodes which collect activity from the surface of the brain. The region of the brain which the electrodes cover is called the speech motor cortex, and controls the muscles of our face, vocal cords, tongue, lips. With the neural signals [that we collect from the electrodes], we can decode the signals to letters, words or sounds. Once these words are on the screen, we can use text-to-speech technology.

The main difference between our technology and the ones you mentioned are that our technology gets information directly from the brain and does not require any motor input. Once we collect the information from the brain, it could have diverse outputs. As mentioned earlier in this talk, we certainly have a long way to go to make this usable for everyday [use]. We are so lucky to have partners like Pancho who have dedicated their time to pushing this project forward.

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## Q: Was the risk worth the benefit? Has the outcome provided all the goals set forth by the prognosticators pre-surgery?

**The UCSF team writes:** The aim of our trial is to prove that this device is safe to be used over many years. So far, we are happy to report that Pancho is doing very well. As for our secondary goals, we set out to see if speech signals were still intact in the speech-motor cortex of an individual who has not spoken for over 15 years. We also proved that this is possible, as Pancho does have a viable speech-motor cortex. Given these goals, we do see that the trial has been a success thus far. That is to say, there is still a long way to go.

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## Q: Where do you go from here?

**The UCSF team writes:** Our biggest hope for the future is to include more participants. We hope that with all the work of Pancho and our other research participants, we can motivate a larger clinical trial with improved hardware to allow for in-home, autonomous use.

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## Q: What is required for someone to learn how to teach a student to use this in the classroom?

**The UCSF team writes:** At this stage of development, this device is not available for use outside of the research setting. However, in the future we hope to create an upgraded device which allows for use in home/school settings so individuals can use it autonomously. Even in this case, there would still be training requirements which would look a lot like what Pancho does now. We would require data collection to train deep learning models which can then recognize words/letters/etc.

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## Q: Is there any danger with the technology that you are developing that would not allow the user down the road to be in control?

**The UCSF team writes:** We do not believe that is a risk in this case. The reason we do not believe this is a risk is because the area of the brain we are covering is only in charge of volitional attempts to speak or move (it does not control involuntary movements or internal speech). However, of course this device and system is in its infancy, and there are times that the system can output incorrect outputs (think typos or incorrect spelling). To answer the question, the device is positioned such that it cannot collect unintended signals.

## Who might benefit from this technology?

### Q: What does this research mean for people who were born with speech-related disabilities, for example, people who never developed speech, as opposed to people like Pancho who lost speech later in life?

**The UCSF team answered:** Unfortunately, this is very hard to determine at this time. We have not found a lot of existing studies to help inform how feasible this would be. Our technology relies on interpreting brain signals that would have normally controlled the vocal tract, so, in its current form, it is unclear how well the approach would generalize to someone who has never spoken. However, if we (and other research groups) are able to continue to find successes in interpreting the speech-related brain activity of people who cannot speak, there may be a way to apply this knowledge to persons who have never spoken. I [David Moses] envision that this would resemble something like a language-learning app. The person would have the brain implant monitoring their activity and would be presented with basic speech targets, such as "ba" or "goo."

The implant software would adapt to their attempts to produce the desired output, and at the same time "neuroplasticity" (a fancy word for the way in which the brain changes over time to learn new things) could enable the user to adapt to the implant. In this way, the user could learn how to speak with the implant as the implant learns how to interpret the brain signals. Eventually, the implant may be able to scale to full speech and not just individual sounds, again similar to the slow methodological process of learning a new language.

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### Q: How realistic is this technology for improving the day-to-day lives of people with speech-related disabilities?

**The UCSF team writes:** Right now, the largest barrier to in-home autonomous use of brain-computer interface technology is the hardware.

As Pancho mentioned, he has an external port on his head which we connect to for research sessions. This port must be kept clean and is only managed by the researchers. We anticipate that with development of improved devices which are fully implanted, these devices will get closer to improving the day-to-day lives of people with speech-related disabilities.

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## Q: Could it be used with children or only adults?

**The UCSF team writes:** Currently, our trial only includes adult participants. However, there is no reason why future versions of this technology couldn't be used in children as well. One of the main goals of our trial is to determine the safety and efficacy of this device to direct future work with broader participant populations.

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## Q: Will something like this be possible for those with neurodegenerative diseases/atrophy from repetitive electrical trauma/repetitive brain injury?

**The UCSF team answered:** We don't have any experience to fully confirm this, but generally, these are the conditions under which we currently feel confident that our approach can work: (1) The user knows how to attempt speech, and (2) The user's speech-motor cortex is intact. Further research is required to understand how well our approach will fare in other scenarios.

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## Q: Have you tried this with children with autism?

**The UCSF team writes:** No, this has currently not been tried in children with autism. There are still more preliminary studies to be done to determine if this approach can be useful in this population. However, we are hopeful that with our work with Pancho, we can prove that this approach is safe and can be helpful for others.

## Q: Are people with cerebral palsy who have communication barriers from birth and motor challenges a likely population for EEG tech?

**The UCSF team writes:** Great question! In our inclusion criteria, we do include participants with cerebral palsy. As mentioned during our presentation, we use the speech-motor cortex of the brain to decode speech. Therefore, if the user knows what he or she intends to say and they have a functional speech motor cortex, we expect that there is the possibility for this approach to be successful.

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## Q: Is this technology accessible for those with tactile defensive systems?

**The UCSF team writes:** For this clinical trial, as long as a participant meets the inclusion / exclusion criteria, and they are interested in participation, they can be enrolled. In the case of tactile defensive systems, this is not something that we have explored in this clinical trial. If you'd like to discuss a specific case, please do not hesitate to reach out at margaret.seaton@ucsf.edu.

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## Q: Would this be helpful for someone with OCD?

**The UCSF team writes:** Currently, this technology has not been tested in individuals with OCD. However, there has been a significant amount of research done on the benefits of deep brain stimulation (DBS) for OCD. Here is the link: https://psych.ucsf.edu/sites/psych.ucsf.edu/files/Information%20Sheet%20for%20DBS.pdf.

# Questions About the Trial

## Q: Why was Pancho chosen for this research? How did you find him?

**The UCSF team writes:** Pancho's neurologist informed him of the new trial when it started, and Pancho volunteered immediately!

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## Q: How much time is Pancho devoting to this research?

**The UCSF team writes:** Pancho is our very diligent collaborator! He spends about 16 hours a week working on speech projects, and about 5-10 hours a week working on the robotic projects.

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## Q: How does he get from Sonoma to UCSF for the study?

**The UCSF team writes:** He doesn't have to make the trip; we go to him! Our equipment, although large at the moment, is mobile. We used to conduct the study in his bedroom, but now we work in a small office very close by.

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## Q: Is Pancho the only research subject? And if so why?

**The UCSF team writes:** Pancho is the first, but he is not the only research participant! We hope to publish more findings in the future, and unfortunately until then I shouldn't say too much about our findings, but I can say that the ability of the approach to work in other persons seems promising to me!

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**Q: ¿Experiencias de uso de CAA en contexto de educación sexual adolescente? (Do you have experience using AAC in the context of adolescent sexual education?)**

**The UCSF team writes:** Great question, we personally do not have any experience using AAC in the context of adolescent sex education. However, it would be so great if AAC could allow for individuals to ask more questions during these types of lessons, and hopefully expansion of this technology to other participant populations could allow for this in the future.

# When will this technology be available?

## Q: When would this technology be available widely?

**The UCSF team writes:** Great question! One of the main goals for our trial is to validate that this type of technology has the potential to be useful for individuals with speech disabilities in the home setting for everyday use. Due to the hard work of Pancho and our other participants, we are working towards this goal. It is hard to anticipate when something like this could be available widely and to individuals not in research projects. However, getting a usable device to as many people as possible is something we are very focused on.

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## Q: You have mentioned the lack of research as a major barrier to addressing many of the challenges people have raised. Can you speak as to what needs to happen to close some of those gaps?

**The UCSF team answered:** Bob, this is a great point. A large thing that can be done is the work that Pancho is doing with us. That is, participating in early feasibility trials is very important! However, of course, not everyone can do this. Another thing to do is to participate in forums like this to let researchers know what the needs are and how we can work to meet them. One important component of getting new research off the ground is identifying needs and showing how this new approach can meet those needs.

**Later on, the UCSF team added:** We think that before studies requiring invasive surgery can be fully justified, it would be very informative to the field to have more noninvasive studies, such as studies with fMRI, EEG, MEG, etc. These acronyms all stand for neuroimaging modalities that don't require surgery, so it is simpler for individuals to volunteer to participate in these studies.

Once a scientific basis is established using these approaches (for example, if someone who has never spoken "tries" to speak, do we see neural activation in speech-motor cortex that in any way resembles what we see with Pancho?), then the science can move from basic understanding to applied and therapeutic-focused studies like the work we're doing with Pancho. This process can take many years, but hopefully as awareness continues to be raised, labs can start getting funding from agencies like the NIH to carry out this important research.

## Can I participate in a trial?

### Q: Will this technology be available to others? Can we get in on any trials?

**The UCSF team answered:** Our goal is to develop technology that will be helpful to anyone who cannot speak and relies on other, much slower technology to communicate. It will take time, but as the research shows us what is possible, we are planning on working towards a clinical solution that people can use in their daily lives.

If you or a loved one is interested in learning more about the trial and participation, please feel free to reach out to Margaret Seaton at margaret.seaton@ucsf.edu.

Please also see the publicly available record at https://clinicaltrials.gov/ct2/show/NCT03698149.

This website gives a bit more information on the inclusion and exclusion criteria for our trial. Thank you!

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### Q: Many people wanted to know whether this technology would work for a specific situation. For example, one person wrote, "Our son only gets to communicate fully 2 times a week for 45 minutes each with a trained communication partner. Can a device like this prove his mind is fully working?"

**The UCSF team answered:** Every case is very different, so we cannot say if a device like this would work for your needs. However, please do feel free to reach out to Margaret Seaton at margaret.seaton@ucsf.edu if you have any specific questions about you or your loved one's case.

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## Q: Is this available on Long Island or in NYC? Can we see if it works with our adult autistic son?

**The UCSF team writes:** For our trial, we require our participants to live locally (within 2 hours of San Francisco). However, there are other Brain-Computer Interface clinical trials across the country. There is one recruiting at Mt. Sinai: https://www.mountsinai.org/clinical-trials/command-early-feasibility-study-efs.

With each clinical trial, they will have specific inclusion/exclusion criteria. If you are interested in a specific clinical trial, I would recommend you reach out to the study coordinator if you can find their information to learn more. As this technology advances, the hope is for these trials to be proven safe in more participant populations so it can be more inclusive.

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## Q: Are there any trials with nonspeaking autistic individuals?

**The UCSF team answered:** Not with a brain implant, but there is a clinical trial at UCSF that works with individuals with autism spectrum disorders, including with nonspeaking autistic individuals. This trial primarily works with children and they are actively recruiting! The lead investigator is Dr. Carly Demopoulos. The link is: https://autismneuro.ucsf.edu/.