

Thesis Project Portfolio

Designing, Fabricating, and Assessing the Efficacy of a BiPAP Mask-mounted Blink-based Communications System

(Technical Report)

Investigating Perspectives of Genomics Professionals on the Privacy & Security of Genetic Data

(STS Research Paper)

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Bachelor of Science, School of Engineering

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Executive Summary

Amyotrophic Lateral Sclerosis (ALS), more commonly known as Lou Gehrig's Disease, is a progressive and fatal neurodegenerative disease affecting motor neurons located in the brain and spinal cord. The rapid deterioration of these neurons in the mid and late stages of ALS can greatly reduce the ability of affected patients to communicate effectively. As the ability to speak decreases, the role of a caretaker becomes increasingly necessary to maintain an acceptable quality of life. Many of the existing communication technologies for people with ALS rely heavily on having a physical caretaker present in the room to act on the needs of patients. Additionally, the decrease in dexterity and range of motion experienced during the later stages of ALS can cause these methods to become less practical.

This technical project sought to develop a blink-based method of communication to improve patient communicatory autonomy and reduce caretaker burden. EyeLoop, an open-source, Python-based eye-tracker software allowing for close-eye tracking, was utilized in conjunction with a proprietary blink-detection algorithm. The entire software was integrated with a small and lightweight Raspberry Pi camera and macro lens attachment. A lightweight mount, designed using the computer-aided design software Fusion 360, was 3D-printed using SLA resin to securely attach the camera system to a traditional BiPAP mask, which are commonly worn by ALS patients to provide ventilatory support and improve sleep quality. The combination of a mounted camera with the blink-detection software hoped to allow ALS patients to promptly signal for caretaker assistance via intentional blinking, which was defined as three quick and prominent blinks.

The overall development of the BiPAP mask-mounted camera system was a success, as the mount was lightweight and held the camera securely to the mask. Additionally, the blink detection software was successfully utilized to track patterns in pupil characteristics and ultimately identify blinking. However, the efficacy of the system in distinguishing intentional from unintentional blinks can

be greatly improved. More work should be done to refine the accuracy of the system especially at high frame rates and in dim lighting, where shadows from the eyebrow made the system fault.

Employment of cameras in the medical field, such as with blink-detection technologies for eye-tracking, have brought significant improvements to treatment approaches and quality of patient life. However, many people are hesitant to sacrifice privacy in their life to any infrastructure so closely intertwined with the government, which is further exemplified by the recent development of gene editing technologies. Genetic information is a fundamental aspect of an individual's identity, providing insights into their ancestral heritage, unique biological traits, and even predispositions to certain diseases. The leakage or mismanagement of such sensitive data could bring about a multitude of ethical privacy concerns such as discrimination in insurance and even potential misuse for nefarious purposes via the engineering of bioweapons or pathogens to target specific vulnerable populations. These concerns highlight the critical need for robust safeguards in genetic data handling and storage.

This STS research project sought to illuminate the perspectives of genomics professionals on topics related to genetic data privacy and security. A survey was conducted on a sample population comprised of 45 doctors, researchers, and undergraduate researchers affiliated with three genomics labs at the University of Virginia. This diverse population represents a range of expertise and perspectives within the field, encompassing professionals with extensive experience in clinical practice and research, as well as emerging scholars at the undergraduate level. The survey consisted of a series of eight structured questions designed to elicit responses on a variety of topics related to genetic data privacy, including concerns about data breaches, confidence in current security measures, perceptions of the need for legislative intervention, and attitudes towards the use of secure technology services. Participants were asked to rate their responses on a scale of 1 to 5, with 1 indicating the lowest level of agreement or concern, and 5 indicating the highest. Overall, the survey results were indicative of a lack of confidence in the ability of existing measures to protect an individual's genetic information. They suggested that this lack of protection enables outside factors such as market competition to influence the decision-making

process of genomics professionals. Additionally, the results highlighted the vital importance that exists in having a well-informed public, whose knowledge of and advocacy for genetic data legislation can play a significant role in shaping future policy decisions.

The results from the survey were quite insightful and should provide great value towards facilitating more comprehensive policies and regulations regarding the collection and utilization of genetic information. To obtain results from 45 participants was crucial in ensuring the study provide comprehensive perspectives. Further research should be done to better understand how these perspectives vary between more urban and rural areas, as well as to evaluate the perspectives patients have on the use and protection of their own genetic data.