TOWARDS A LARGE-SCALE AUDIO-VISUAL CORPUS FOR RESEARCH ON AMYOTROPHIC LATERAL SCLEROSIS

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Background

- Amyotrophic Lateral Sclerosis (ALS) is a heterogeneous, neurodegenerative disorder that affects speech, swallowing, and motor functions
- The median survival time from onset to death ranges from 20 to 48 months with 12–18 months to diagnose [1]
- Research has shown that speech- and face-based measures of people with ALS from conversational speaking have the potential to serve as endpoints in clinical trials and in diagnostics of disease progression [2][3]

Objective

- This presentation describes the creation of a large, open data platform, comprising speech and video recordings of people with ALS and healthy volunteers
- Each participant is interviewed by Modality.AI’s virtual agent, emulating the role of a neurologist or speech pathologist walking them through speaking exercises [Fig 1]
- The collected data is made available to the academic and research community to foster acceleration of the development of biomarkers, diagnostics, therapies, and fundamental scientific understanding of ALS

Design and Method

- Recruitment is done through Peter Cohen Foundation, 501(c)(3) non-profit organization functioning as EverythingALS.org, with over 2000 subscribers growing 25% month over month
- Each person with ALS is paired with a healthy volunteer as well as one of the program’s student ambassadors, who are pre-med or science students rendering support to participants
- Each participant engages in weekly recording sessions, for about ten minutes, and video recordings of the subject’s face, full-duplex audio recordings, audio and facial measures, measurement of progression using self-reported ALSFRS-R and ROADS, and demographic information are collected
- Researchers can access the collected data in real-time through an open data platform accessible via the cloud [Fig 2]

Results

- Within seven months, the collection was designed, IRB-approved, recruitment launched, and over 100 participants were enrolled and recorded in regular sessions [Fig 1]
- This decentralized trial enabled participation in the home setting which resulted in a broader catchment with better granularity (more frequency) than typical site-based studies

Conclusion

- We present the genesis and steps towards a large-scale audio-visual database for ALS research
- By August 2021, we project a total of 1000 participants will be included [Fig 5]
- A series of data post-processing and standardization steps will be undertaken to produce the largest and most comprehensive audio-visual ALS database covering a large geographic area [Fig 4] available for use by the research community
- By removing data barriers, many researchers can work on the same data simultaneously, hence accelerating the development of early diagnosis and therefore early interventions, which is critical given the short lifespan from disease onset in ALS

References

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