

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**

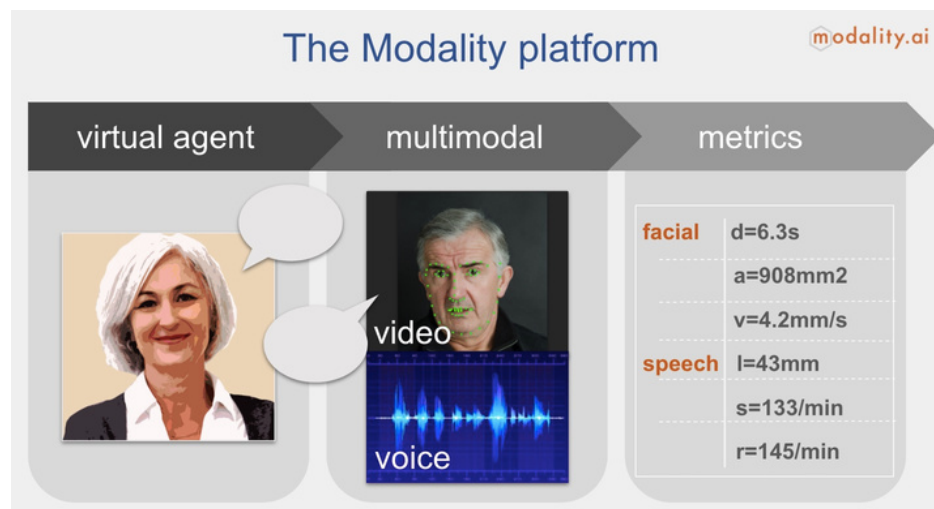


Figure 1: Modality.ai platform

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]

Unlocking data for accelerated biomarker discovery

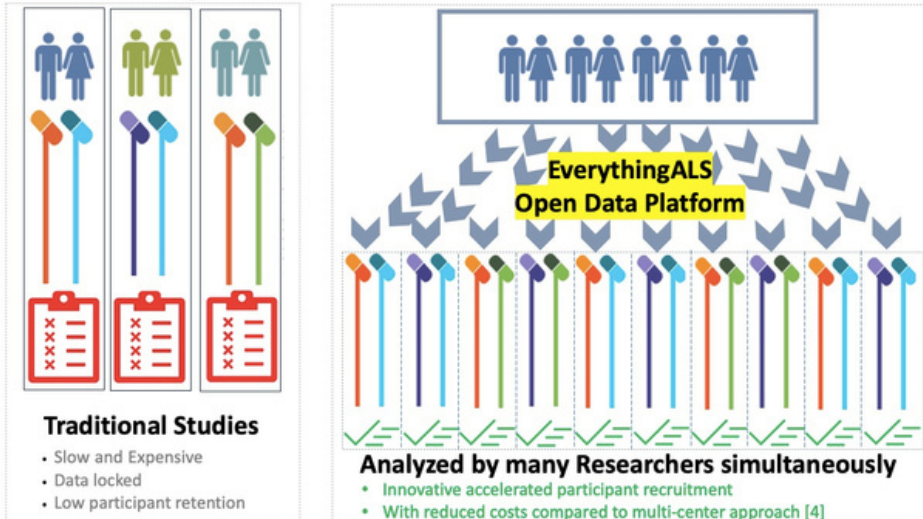


Figure 2: Benefits of EverythingALS's open data platform approach

Results

- Within seven months**, the collection was designed, IRB-approved, recruitment launched, and **over 100 participants were enrolled** and recorded in regular sessions [Fig 3]
- 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

TIMELINE



Figure 3: Timeline from inception to projected enrollment of 1000 participants

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**

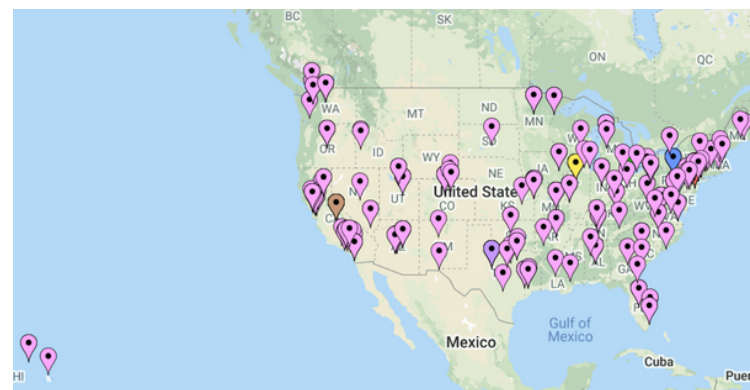


Figure 4: Participant geography location

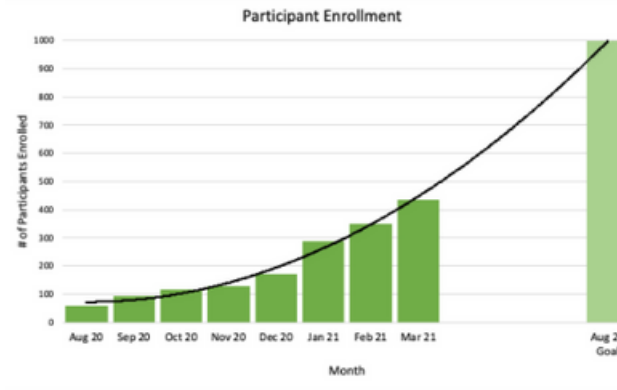


Figure 5: Participant enrollment rate by month

References

