

“I’m not drunk,  
I’m not stupid,  
it’s ALS”

HOW TO CONDUCT  
QUALITATIVE  
RESEARCH WITH  
PEOPLE WITH  
COMMUNICATION  
DIFFICULTIES

MATT GRIFFITH, MD, MPH; AMELIA CALDER, MS, CCC-SLP; MARCIE LEE, MPH, MA

# Disclaimers

---

*The views expressed in this presentation are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.*

*There are no relevant financial relationships to report related to this research. This research was supported by the Department of Defense Congressional Medical Research Program.*

*This study was approved by the Colorado Multiple Institutional Review Board (COMIRB #21-5071).*

# Outline

---

ALS and Associated Respiratory Syndromes

---

Ethical and Social Justice Imperatives for Including People with Difficulty Speaking (Dysarthria) in Research

---

Dysarthria Phenotypes and Techniques for Engaging with People who Have Dysarthria

---

Qualitative Research Considerations for Research Subjects with Dysarthria

---

Future Directions

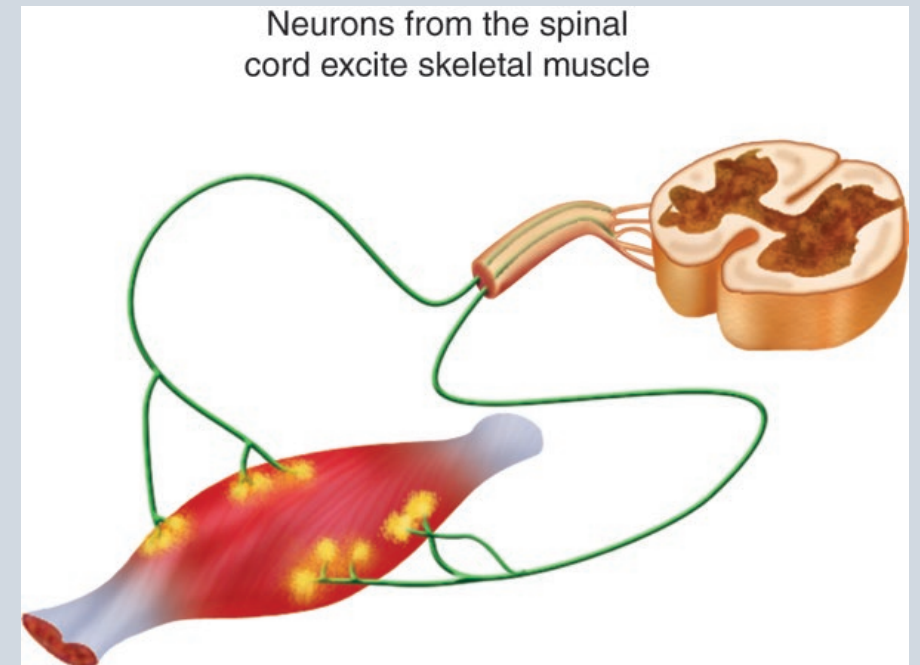
# Amyotrophic Lateral Sclerosis (ALS)

ALS is a rare, progressive, and fatal disease that affects a person's ability to control their skeletal (voluntary) muscles including those that control swallowing and breathing.

- Occurring in 2 per 100,000 people per year in US.<sup>1</sup>

The risk of developing ALS is increased for those with a history of military service regardless of country served.<sup>2-4</sup>

ALS leads to 100% service connection for Veterans once diagnosed, regardless of era or length of service.

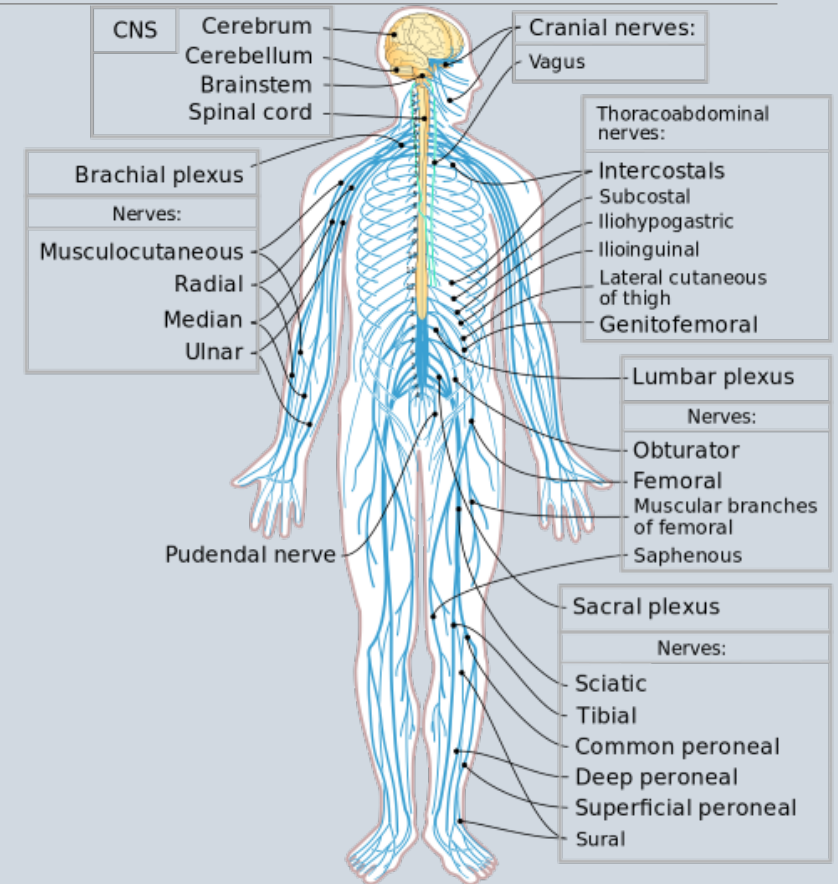


# Progression of ALS

ALS can progress rapidly or slowly and can either begin by affecting muscles that affect speech and swallow or muscles in the limbs.

Some patients live only a few months following diagnosis while others live for decades.

- Most people will live 2-4 years following diagnosis<sup>1</sup>.

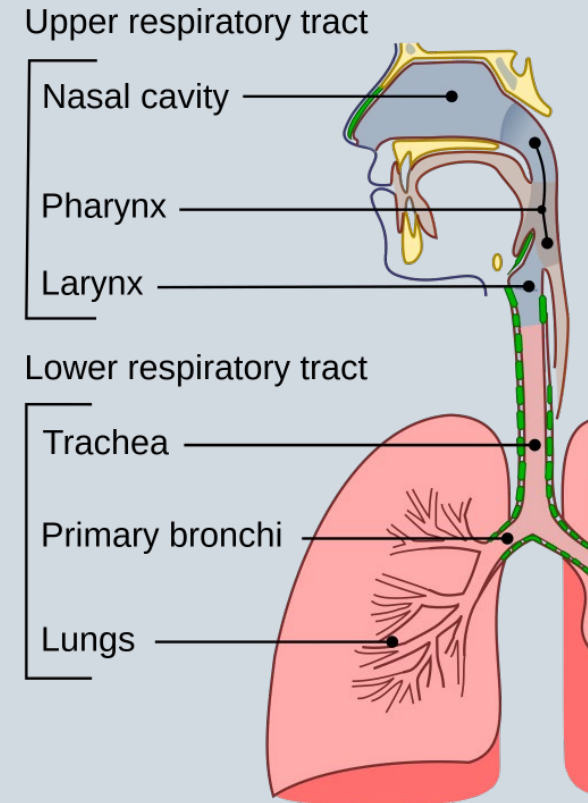


# Respiratory Syndromes of ALS

80% of people with ALS will die from respiratory complications of the disease.<sup>1-2</sup>

ALS does not affect the lungs but it affects:

- Pharynx: controls swallowing.
- Larynx: controls speaking and protects the lungs from food, saliva, and other potentially infectious swallowed material.
- Diaphragm: controls breathing.



# Respiratory Syndromes of ALS

---

Diaphragm strength is a predictor of survival in ALS and determines when people with ALS are prescribed assistive breathing devices that help compensate for diaphragm weakness<sup>1-2</sup>.

Diaphragm strength is measured using a spirometer.



# Home Spirometry

Spirometers are usually located in pulmonary function laboratories inside of hospitals or clinics.

Recently, handheld spirometers have become widely available, creating the possibility that patients could perform testing in their homes.

We sought to evaluate a home-based testing strategy for measuring lung function among people with ALS.





# Study Design

---

We sought to evaluate 4 aspects of home spirometry for patients with ALS:

- Test Quality.
- Cost.
- Provider Preferences.
- Patient Preferences.

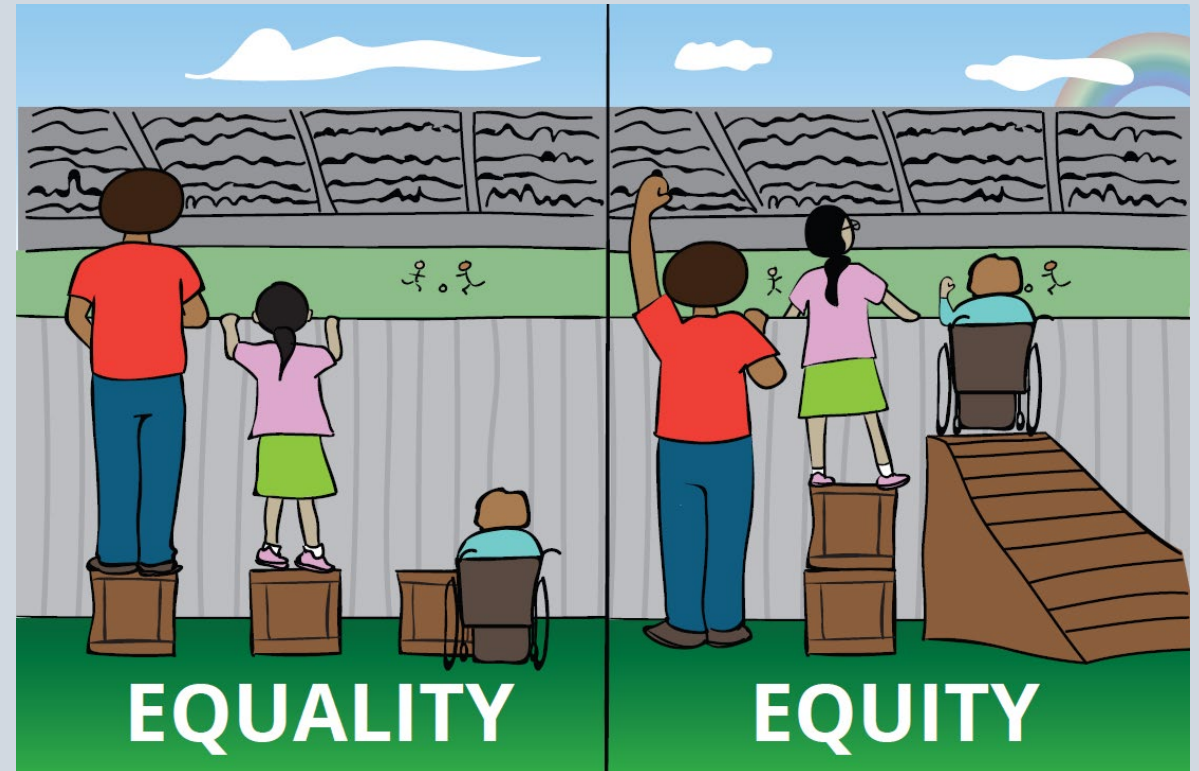
# Patient Preference – Ethics and Equity

Patients with disabilities are often excluded from clinical research.

Patients with dysarthria are a group of people who are easy to exclude from qualitative research.

VA mission is to serve “all” Veterans, including those with disabilities and dysarthria.

Exclusion leads to inequitable access to care, development of research-based care plans that may not be the best fit for this population, and lack of opportunity to benefit from research innovation.



# Patient Preference – Ethics and Equity

---

It was important to our group to include all patients with ALS regardless of speaking ability.

Experience of patients with dysarthria is no less important to our research and to our clinical improvement goals.

We are all new to research in this space, so we quickly realized that we needed to bring someone with expertise working with people with dysarthria to help us improve our research methods.



# Dysarthria- The Focus of Our Discussion Today

Per American Speech Language Hearing Association (ASHA)-  
**Dysarthria** refers to a group of neurogenic speech disorders characterized by “abnormalities in the strength, speed, range, steadiness, tone, or accuracy of movements required for breathing, phonatory, resonatory, articulatory, or prosodic aspects of speech production”<sup>1</sup>

1- [https://www.asha.org/Practice-Portal/Clinical-Topics/Dysarthria-in-Adults/#collapse\\_1](https://www.asha.org/Practice-Portal/Clinical-Topics/Dysarthria-in-Adults/#collapse_1)

# Perceptual Characteristics of Dysarthria

---

- Strained/strangled, breathy, or rough vocal quality.
- Hypernasality.
- Slow rate of speech or short rushes of speech.
- Imprecise or inconsistent articulation (slurred speech).
- Reduced pitch variance (lack of inflection, voice sounds “flat”).
- Reduced vocal loudness (sounding really quiet).

# Causes and Prevalence of Dysarthria

---

- Amyotrophic Lateral Sclerosis (~80%).
- Multiple Sclerosis (40%-51%).
- Parkinson's Disease (44%–88%).
- Huntington's Disease (78%–93%).
- Stroke (22%-58%).
- TBI (30%-86%).
- Other causes include myasthenia gravis, muscular dystrophy, non-fluent variety of primary progressive aphasia, brain tumors, cerebral palsy, Guillen-Barre syndrome.

# Common Concerns for Individuals with Communication Difficulties

---

- Difficulty being understood.
- Having to repeat themselves.
- People not waiting for them to finish speaking.
- Fatigue with speaking.
- Interrupting or guessing what they are trying to say as they are speaking.
- Choosing to participate less in discourse due to fatigue or speech feeling effortful.

# Commonly Reported Experiences from Veterans with Dysarthria

---

- They always ask my wife instead of me, it's like I'm invisible.
- It's just not worth talking anymore, no one understands me.
- It's too exhausting to try and talk.
- People don't want to wait for me to finish, so why bother.
- I can't talk on the phone anymore, but I hate relying on others to do it for me.



# Communication Tips

---

- Don't pretend to understand if you didn't (the smile and nod). Just ASK ("I didn't catch that; do you mind repeating what you said?").
- It can feel uncomfortable to point out that their speech is difficult to understand, but most people are aware and by communicating this, you are sharing that you value what the person has to say.
- Repeat back what you DID hear so they only have to clarify what was missed (I heard you say something about difficulty with breathing but didn't understand the first few words").
- Ask yes/no questions or multiple-choice questions.
- Fatigue can be a huge factor and is not always obvious- ask if they're getting tired or offer breaks/shorter sessions.
- Ask them to over articulate if speech is slurred and you're missing what they are saying ("would you mind exaggerating your mouth movements so I can get what you're saying" - can also model for them).
- Can be helpful to have caregiver present. \*Always ask before deferring to caregivers.

# Communication Tips

---

- Preface how you will be asking the questions (“I’m going to ask you some questions and also provide you with some specific options to hopefully make communication easier”).
- Cue people to provide shorter responses.
  - Common for people to reply w/lengthy responses unless prompted, but then become fatigued/unintelligible quickly.
  - E.g., when asked "How many years did you serve in the military? Which branch of service?" Response may be “oh, I served in the military for about 25 years, it was a long career, but I was only 45 when I got out. I was in the army but never had to go overseas and was so glad to get out in '76 or was it '77?” vs “25 years, army”.

# Alternative Communication Options

---

- Use chat box on VVC or Teams calls.
- Encourage veterans to write out answers on note pad or whiteboard (if they have one).
- Some folks have assistive and augmentative communication (AAC) devices/programs/apps.
  - Ask/encourage them to utilize if appropriate.
  - Many people that have AAC don't use unless prompted.

# Practical Applications for Qualitative Research

## Iterative Process:

- Drill down on what is important and what is the data we need to get from interviews (guided by methodologist and PI).
  - Prioritize questions that are to be asked for each Veteran.
  - Send the participant priority questions through REDCap to answer beforehand. Use interview to review REDCap answers for clarity.
- Document information about the participant each time there is an interaction with them.
  - These notes will be reviewed with the qual team before the interviews.
  - Provide opportunity for the PM and PRA to discuss concerns and how to best address them.
- Determine the factors involved and the best approach for each interview.

# Best Practices for Before the Interview

---

- Send priority questions beforehand to have Veteran write out responses.
- Use their preferred platform to conduct the interview.
- Allow caregiver to join interview for help with communication.
- Determine from previous interactions and healthcare notes if they use technology to help them communicate (i.e., assistive and augmentative communication (AAC) devices/programs/apps).
  - Alternatively, encourage use of a whiteboard.
- Schedule meetings with the team to discuss the Veteran before the interview.
- Use “Respectful and courteous ways to communicate” document.

## Respectful and courteous ways to communicate with Veterans who have their speech affected by ALS

- Avoid pretending to understand if you missed something they said. It is not nice nor is it polite.
- Ask for specific clarifications in a polite and respectful manner.
  - You can say - *so sorry, I didn't catch that, I heard something about x and y, what is the part I am missing?*
- Reference the communication throughout the interaction
- Acknowledge that this is a speech-related issue, not a cognitive one
- Encourage the veteran to exaggerate their mouth movements to make their speech more clear

# Best Practices During the Interview

---

Less open-ended questions.

- "In a few words, can you tell me...."; yes or no questions.
- If sent questions before interview.
  - Probe on responses during interview.
  - Ask the non-priority questions if participant is able to, and if time permits.
- If caregiver present, check with Veteran if they agree with caregiver responses.
- Have a notetaker to assist interviewer.
  - Take notes
  - Look at visual cues (looking to caregiver for response, signs of fatigue, physical gestures as answers).
- Limit interview time to 30 minutes or less.
- Check in often; offer breaks; offer multiple meetings with participant if needed.

# Considerations for Study Design

---

- Recruitment for Veterans with communication difficulties in research.
  - Include caregivers?
    - Support Veteran communication
    - Caregiver experience separately
- Consenting Veterans with communication difficulties in research.
  - Teams/VVC consents, in-person
  - Written and verbal response options

# Considerations for Analysis

---

- Social Constructivism Philosophical Framework.
  - Flexibility in communication and data collection.
- How to look at written answers and verbal answers and incorporate them together.
  - Triangulation between written and verbal answers.
  - Go back to veteran or caregiver to ask for clarification.
- Caregivers sharing different experience.
  - Whose experience is being shared.
    - Whose voice is dominant.



# Future Directions: Speech Therapist Involvement in Clinical Research

- Promotes inclusion of patients regardless of speaking ability.
- Include as consultant when writing grants that include qualitative research among patients suspected to have limited speech abilities or known dysarthria.
  - Salary Support: Speech therapists are unlikely to have protected research time or the ability to engage in research during clinical time.
- Iterative process of increasing involvement leading to increased ability to participate in future projects.
- Identify Speech Therapists at your facility interested in research to assist in project development and planning.
  - Clinical relationships.
  - Identify supervisors to help identify potential partners.

# Questions?

---

- Matt Griffith
  - [Matthew.Griffith@va.gov](mailto:Matthew.Griffith@va.gov)
- Marcie Lee
  - [Marcie.Lee@va.gov](mailto:Marcie.Lee@va.gov)
- Amelia Calder
  - [Amelia.Calder@va.gov](mailto:Amelia.Calder@va.gov)

Special thanks to other team members: Amber Lane, Summer Huang, and Rachel Johnson.

# Additional Resources

---

[https://www.asha.org/Practice -Portal/Clinical-Topics/Dysarthria-in-Adults/#collapse\\_1](https://www.asha.org/Practice-Portal/Clinical-Topics/Dysarthria-in-Adults/#collapse_1) +Duffy motor speech book\*

[https://www.asha.org/Practice -Portal/Clinical-Topics/Dysarthria-in-Adults/#collapse\\_1](https://www.asha.org/Practice-Portal/Clinical-Topics/Dysarthria-in-Adults/#collapse_1)