D - Neuro - Amyotrophic Lateral Sclerosis (ALS)

Please complete the survey below.

Thank you!

1. Gold Standard Diagnosis

Does the participant have Amyotrophic Lateral Sclerosis (ALS)?

- ◯ Yes
- ◯ No
- ◯ Not certain

How was this diagnosis confirmed? (Check all that apply)

- ☐ Progressive motor impairment documented by history or repeated clinical assessment, preceded by normal motor function
- ☐ Presence of UMN and LMN signs in at least 1 body region (with UMN and LMN dysfunction noted in the same body region if only one body region is involved) or LMN dysfunction in at least 2 body regions
- ☐ Investigations excluding other disease processes

Does the participant meet the diagnostic criteria for Amyotrophic Lateral Sclerosis (ALS) based on:

(1) Progressive motor impairment documented by history or repeated clinical assessment, preceded by normal motor function;

- ◯ Yes
- ◯ No
- ◯ Not certain

(2) presence of UMN and LMN signs in at least 1 body region (with UMN and LMN dysfunction noted in the same body region if only one body region is involved) or LMN dysfunction in at least 2 body regions;

- ◯ Yes
- ◯ No
- ◯ Not certain

(3) investigations excluding other disease processes.

- ◯ Yes
- ◯ No
- ◯ Not certain

Does the participant meet the diagnostic criteria for Amyotrophic Lateral Sclerosis (ALS) based on the criteria above?

_____

2. Type of ALS

Specify the type of ALS in the participant:

- ◯ Sporadic ALS
- ◯ Familial ALS
- ◯ Spinal/limb-onset ALS
- ◯ Bulbar-onset ALS

If you selected "Familial ALS", please specify the genetic mutation if known:

_____

3. Etiology

What is the suspected or known etiology of ALS in the participant?

- ☐ Genetic factors
- ☐ Environmental factors

Genetic Factors

- ☐ C9orf72 mutation
- ☐ SOD1 mutation
- ☐ Other genetic factors

If you selected "Other genetic factors", please specify: _____

If you selected "Environmental factors", please specify: _____

4. Clinical Presentation

Describe the clinical features and symptoms of ALS in the participant:

- ☐ Upper Motor Neuron Signs (e.g., spasticity, hyperreflexia)
- ☐ Lower Motor Neuron Signs (e.g., muscle weakness, atrophy, fasciculations)
- ☐ Bulbar Symptoms (e.g., dysarthria, dysphagia)
- ☐ Respiratory Involvement

5. Disease Progression

Please provide information on the current stage and progression of ALS:

- ◯ Early Stage
- ◯ Intermediate Stage
- ◯ Advanced Stage

6. Neurological Assessment

Please provide results from relevant neurological assessments:

Revised ALS Functional Rating Scale (ALSFRS-R) score: _____

Forced Vital Capacity (FVC) percentage (if measured): _____

Other neurological assessment (please specify): _____

7. Imaging and Diagnostic Tests

Electromyography (EMG) and Nerve Conduction Studies (NCS): _____

Magnetic Resonance Imaging (MRI) of the brain and spinal cord:

Lumbar Puncture (if performed, specify findings): _____

Genetic testing (if applicable, specify results): _____

Other diagnostic tests (please specify):

_____

8. Treatment and Management

Has the participant undergone any treatment or interventions for ALS?

◯ Yes
◯ No

Yes

☐ Medications
☐ Supportive Care

Medications (if applicable):

☐ Riluzole
☐ Edaravone
☐ Sodium phenylbutyrate/taurursodiol
☐ Tofersen
☐ Symptomatic treatment (e.g., for spasticity, pain)
☐ Other

If you selected "Other", please specify:

_____

Supportive Care:

☐ Physical therapy
☐ Occupational therapy
☐ Speech therapy
☐ Respiratory support (e.g., non-invasive ventilation)
☐ Nutrition and swallowing support
☐ Psychotherapy
☐ Other

If you selected "Other", please specify:

_____