

## ▼ Worksheet Snapshot (31 Aug 2023)

### Data Collection Admin Fields

- Context Date for the Encounter
- Date and Time of Encounter Creation
- Data Collector
- Site

### Demographics and Education

- Please give details of Data Source(s) used for this page
- Date of Birth
- Sex of Person with ALS
- How long have you lived at your current address?
- What best describes the area in which you live?
- What is your current marital status?
- How many children do you have?
- Children's Details
- What are your current living arrangements?
- What is the highest level of education that you have completed?
- Total number of years in education  
(does not need to be continuous)?

### Ancestry and Family History

- Please give details of Data Source(s) used for this page
- What is your place of place of birth?
- What is your biological father's place of birth?
- What is your biological mother's place of birth?

- What is your paternal grandfather's place of birth?
- What is your paternal grandmother's place of birth?
- What is your maternal grandfather's place of birth?
- What is your maternal grandmother's place of birth?

## **Biological Relatives**

- Do/Did you have siblings
- Is the participant a twin?
- Does/Did your Father have siblings (Paternal Uncles / Aunts)
- Does/Did your Mother have siblings (Maternal Uncles / Aunts)

## **Family Medical History**

- Neurological Conditions of Interest include the following:  
ALS/MND, Dementia, Parkinsonism, Anxiety, Social Anxiety, Post Traumatic Stress, Excessive Alcohol Use / Alcoholism, Phobias, Drug addiction, Gambling addiction, Eating Disorder, Psychosis, Attention deficit disorder / hyperactivity, Bipolar disorder, Depression, Obsessive Compulsive disorder, Personality disorder, Schizophrenia, Autistic Spectrum Disorder (ASD), Dyslexia, Learning Disability

Have any of your biological family members been diagnosed with any Neurological Conditions of Interest listed above?

## **Limited Knowledge of Family History**

- Are any of the following scenarios of limited family history knowledge applicable:

## **Medical History**

- Please give details of Data Source(s) used for this page
- Have you ever been diagnosed with Diabetes?
- Age at diagnosis
- Type of diabetes and details of any medications ever used

- Have you ever been diagnosed with raised cholesterol?
- Age at diagnosis
- Details of any medications ever used for Raised Cholesterol
- Have you ever been diagnosed with any Psychiatric Condition?
- Details of Psychiatric Condition(s)
- Have you ever been prescribed Anti-Anxiety / Anti Depressant medications?
- Details of Anti-Anxiety / Anti Depressant medications
- Have you ever been prescribed Anti-Psychotic medications?
- Details of Anti-Psychotic medications
- Have you / had you any additional co-morbid conditions?
- Details of Co-morbid Condition(s)

## **Smoking and Alcohol**

- Please give details of Data Source(s) used for this page
- Have you ever smoked?
- Do you currently smoke? If not, please enter the date you stopped
- Forms, amount and duration of smoking
- Smoking Pack Years (WIP)
- Have you ever vaped / used E-cigarettes?
- Do you currently vape? If not, please enter the date you stopped
- How many days does/did a bottle of e-liquid last
- What is the size of the bottle
- Number of years
- Have you ever drank alcohol?

- Do you currently drink? If not, please enter the date you stopped
- How often do/did you drink alcohol?
- Has your drinking ever been considered problematic by yourself or others?

## **Baseline Clinical Data**

- Please give details of Data Source(s) used for this page
- Gold Coast Diagnostic Criteria?
- Date of Onset of Symptoms
- Date of ALS Diagnosis
- Interval from onset to diagnosis
- Site of onset
- First Symptoms
- Approximate weight before the onset of ALS symptoms
- Height
- Were Diagnostic EMG/Nerve Conduction Studies performed
- Date of Diagnostic EMG/Nerve Conduction Studies performed

## **Clinical Progression Data**

- Please give details of Data Source(s) used for this page

## **Clinical Visit Details**

- Date of Specialist ALS Clinic Visit
- Allied Health Professionals seen during specialist ALS Clinic Visit
- Was Weight assessed?
- Date Assessed
- Current weight

## Interventions

- Gastrostomy in situ
- Parenteral Nutrition
- Non-invasive Ventilation
- Were Respiratory Tests performed?
- Forced Vital Capacity (FVC)
- Sniff Nasal Inspiratory Pressure (SNIP)
- Slow Vital Capacity (SVC)
- Maximal Inspiratory Pressure (MIP)
- Maximal Expiratory Pressure (MEP)
- Peak Cough Flow (PCF)
- Arterial Blood Gases (ABG)
- Was ALSFRS-R assessed?
- Date Assessed
- Assessment Type
- Speech
- Salivation
- Swallowing
- Handwriting
- 5a. Cutting food and handling utensils (participants without gastrostomy)
- 5b. Cutting food and handling utensils (participants with gastrostomy)
- Dressing and hygiene
- Turning in bed and adjusting bed clothes
- Walking
- Climbing stairs
- Dyspnea

- Orthopnea
- Respiratory insufficiency
- ALSFRS-R Subtotals
- ALSFRS-R Total & Staging
- Revised El Escorial (Airlie House)
- Aids or appliances in use due to the symptoms associated with your ALS
- Was EQ-5D-5L assessed?
- Date Assessed
- Assessment Type
- Mobility
- Self-Care
- Usual Activities
- Pain / Discomfort
- Anxiety / Depression
- Overall Health Status

### **Disease Modifying Drugs**

- Please give details of Data Source(s) used for this page
- Have you ever taken any Disease Modifying Medications?
- Which disease modifying medications have you taken?

### **ALS Symptomatic Medications**

- Please give details of Data Source(s) used for this page
- Are you currently taking ALS Symptomatic Medications?
- What medications do you currently take due to the symptoms associated with ALS?

- Have you had any Hospital Based Therapeutic Interventions as part of your treatment for ALS since your last clinic review?
- Which of the following hospital Based Therapeutic Interventions have you had since your last clinic review?

## **Cognition and Behaviour**

- Please give details of Data Source(s) used for this page
- Was Cognitive Screening performed
- Please give details of the cognitive assessments
- Was Behavioural Screening performed
- Please give details of the behavioural assessments
- Does the person have Dementia
- Source of Diagnostic Dementia Information
- Type of Dementia
- Date of Diagnosis

## **Socio-Economic Details**

- Please give details of Data Source(s) used for this page
- Does your household own or have access to a car/van?
- Does your household own or rent your accommodation
- Do you currently have private health insurance
- Approximate Net household income for the last year
- How would you describe your present principal status
- Age at which work was commenced full-time

## **Employment Status (New Version)**

- Which of the following best describes your employment status before the onset of symptoms associated with your condition

## **Employment Status (Old Version)**

- Which of the following best describes your employment status before the onset of symptoms associated with your condition
- Which of the following best describes your current employment status?

## **Employment Status Change (Old Version)**

- Has there been a change in employment status
- Reason for Change in Employment Status
- Date of Change in Employment Status
- Do you receive any state benefits due to your condition?
- Details of State Benefits
- Have you received a grant(s) / support(s) from a charity dedicated to your condition?
- How much approximately?
- How often is this received
- Does a family member(s) or friend(s) help you with tasks within your own home which you couldn't do because of your condition
- Details of Caregivers

## **Resource Use**

- Please give details of Data Source(s) used for this page
- Have you used any community based health services used in the past four months/since last interview?
- Have you used any social care services used in the past four months/since last interview?
- Have you used any specialist palliative care services used in the past four months/since last interview?
- Have you used any counselling services used in the past four months/since last interview?



- Have you had any hospital outpatient appointments in the last four months/since last interview?
- Have you had any visits to hospital accident and emergency departments in the past four months/since last interview?
- Have you had any overnight stays in hospital in the past four months/since last interview?
- Have you received any aids or appliances due to the symptoms associated with your ALS?
- Have you or your household spent any extra money in order to access treatment?
- Have you or your household made any home, car or other modification because of your illness?
- Were there any additional costs (including telephone charges, electricity and heating, food and drink, clothes, vitamins and supplements, transport costs, other) that you or your household spent on (due to your condition) in the past four months/since last interview?
- Have you or your household spent on additional complementary or alternative medicine (due to your condition) in the past four months/since last interview?

## **Genetic Testing Information**

- Please give details of Data Source(s) used for this page
- Was Accredited Diagnostic Gene Testing Performed
- Please give details of the Accredited Diagnostic Gene Testing
- Was Non-Accredited Research Gene Testing Performed
- Please give details of the Non-Accredited Research Gene Testing
- Was Whole Genome Sequencing Performed
- Date Whole Genome Sequencing was performed

## **Linked IDs**

- Please give details of Data Source(s) used for this page

- Local ALS Register ID
- DNA Bank ID
- Has the participant been enrolled in any clinical trial(s)?

## **Endpoints and Vital Status**

- Please give details of Data Source(s) used for this page
- Participant Vital Status