Visit type	Module	Variable text	Variable endstats	Change and date
NB: Fields that form part of the minimum dataset are highlighted in bold.				
First Visit/Subsequent visit	Patient Information			
First Visit/Subsequent visit		Visit Date	formatted date	
First Visit/Subsequent visit		MND Clinical Site	(drop down)	
First Visit/Subsequent visit		Date consent obtained (if in clinic)	formatted date	Field added 11/8/22
First Visit/Subsequent visit		Consultation type	(radio) standard/telehealth	
First Visit/Subsequent visit		Telehealth Consultation	(radio) telephone/video/email or online	
First Visit/Subsequent visit		Height (in cm)	Integer (number)	
First Visit/Subsequent visit		Weight (in kg)	Integer (number)	
First Visit/Subsequent visit		BMI	auto-calculated field	
First visit/ Completion	Diagnosis details	Diagnosis	(radio) Undifferentiated |ALS-Bulbar Onset | ALS-Cervical Onset | ALS-Thoracic Diaphragmatic Onset | ALS-Lumbar Onset | Flail arm | Flail leg | PLS |	
Subsequent Visit		Has the diagnosis changed since last visit?	(radio) Yes | No	Field added 13/6/22
Subsequent Visit		Please confirm the diagnosis	(radio) Undifferentiated |ALS-Bulbar Onset | ALS-Cervical Onset | ALS-Thoracic Diaphragmatic Onset | ALS-Lumbar Onset | Flail arm | Flail leg | PLS |	Field added 13/6/22
First Visit/ Subsequent Visit		MND confirmed by	(radio) Neurologist | Specialist Physician | General Practitioner | Other	Field added to SV 13/6/22
First Visit/ Subsequent Visit		Please specify	text	Field added to SV 13/6/22
First Visit/ Subsequent Visit		More than one opinion given?	(radio) Yes | No	Field added to SV 13/6/22
First Visit/ Subsequent Visit		Tests to assist with diagnosis	(checkbox) MRI Brain | MRI Cervical Spine | MRI Lumbar Spine |	Field added to SV 13/6/22

			EMG/NCS | Lumbar Puncture | Other	
First Visit/ Subsequent Visit		Please specify	text	Field added to SV 13/6/22
First Visit	Presenting details	Ethnicity	(radio) European / Caucasian | Asian | Aboriginal / Torres-strait Islander | Americas | Oceania | Other	
First Visit		Date of symptom onset	formatted date	
First Visit		Region where symptoms began	(radio) Bulbar | Cervical | Chest/Abdomen |Lumbar |other	
First visit		Please specify	text	
First Visit		Located	(radio) Left hand side | Right hand side |Both	
First Visit		Please specify	text	
First Visit		Dominant Hand	(radio) Left/ Right/Both	
First Visit		Type of MND / Diagnosis	(radio) Familial |Sporadic/ Unknown	
First Visit		Date MND Confirmed	formatted date	
First Visit	Medical History	Status of mother at time of clinic visit	(Drop Down)	
First Visit		Age at Death (if known)	Integer (number)	
First Visit		Age of Mother at time of clinical visit (if known)	Integer (number)	
First Visit		If Age of mother at time of clinical visit is unknown or N/A, check this box	(checkbox)	
First Visit		Status of father at time of clinical visit	(Drop Down)	
First Visit		Age at Death (if known)	Integer (number)	
First Visit		Age of Father at time of clinical visit (if known)	Integer (number)	
First Visit		If Age of father at time of clinical visit is unknown or N/A, check this box	(checkbox)	

First Visit		Mother dementia status (patient report)	(radio) Yes | No |Unknown	
First Visit		Father dementia status (patient report)	(radio) Yes | No |Unknown	
First Visit		Ever smoked?	(radio) Yes | No	
First Visit		Packs x Years	Integer (number)	
First Visit		Current smoking status	(radio) Yes | No	
First Visit		Co-morbidity: Other psychiatric conditions (select all that apply)	(checkbox) N/A | Depression | Anxiety | Dementia | Schizophrenia | Other	
First Visit		Please Specify	text	
First Visit		Co-morbidity: Other medical conditions (select all that apply)	(checkbox) N/A | Diabetes | Heart disease | Hypertension | asthma | Cancer | Other | Other| Other| Other	1/4/22 Addition of 2x 'Other' fields
First Visit		Please Specify	text	
First Visit		Please Specify	text	
First Visit		Please Specify	text	
First Visit		Please Specify	text	
First Visit		Highest educational attainment (select one)	text	
First Visit		Occupation	(Drop down)	
First Visit/Subsequent visit	Region(s) affected by MND ALS	Bulbar Region - UMN	(drop down) Yes | No	
First Visit/Subsequent visit		Bulbar Region LMN	(drop down) Yes | No	
First Visit/Subsequent visit		Cervical Region - UMN	(drop down) Yes | No	
First Visit/Subsequent visit		Left, Right or Both	(drop down) Left | Right | Both	
First Visit/Subsequent visit		Cervical Region - LMN	(drop down) Yes | No	
First Visit/Subsequent visit		Left, Right or Both	(drop down) Left | Right | Both	
First Visit/Subsequent visit		Lumbar Region - UMN	(drop down) Yes | No	
First Visit/Subsequent visit		Left, Right or Both	(drop down) Left | Right | Both	
First Visit/Subsequent visit		Lumbar Region-LMN	(drop down) Yes | No	

First Visit/Subsequent visit		Left, Right or Both	(drop down) Left | Right | Both	
First Visit/Subsequent visit	Reflexes	Upper Limbs - Biceps: Left	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit		Upper Limbs - Biceps: Right	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit		Upper Limbs - Supinator: Left	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit		Upper Limbs - Supinator: Right	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit		Lower Limbs - Knee: Left	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit		Lower Limbs - Knee: Right	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit		Lower Limbs - Ankle: Left	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit		Lower Limbs - Ankle: Right	(drop down) Hyper Reflexive | Normal | Absent	
First Visit/Subsequent visit	ALSFRS-R Calculator	Speech	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Salivation	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Swallowing	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Handwriting	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Do you have Gastrostomy / PEG?	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Cutting Food and Handling Utensils	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Cutting Food and Handling Utensils	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Dressing and Hygiene	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Turning Bed and adjusting Bed clothes	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Walking	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Climbing Stairs	(drop down) 0 | 1 |2 | 3 | 4	

First Visit/Subsequent visit		Difficulty of Breathing	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Difficulty of breathing when lying flat	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit		Respiratory Insufficiency	(drop down) 0 | 1 |2 | 3 | 4	
First Visit/Subsequent visit	ALSFRS-R Score	ALSFRS Score	auto-calculated field	
First Visit/Subsequent visit	My Recent Symptoms	Please select if form completed by Healthcare Professional	Check box	Added 5/6/23
First Visit/Subsequent visit		Date Symptom scale completed	formatted date	
First Visit/Subsequent visit		Fatigue	(slider) 0-10	
First Visit/Subsequent visit		Pain	(slider) 0-10	
First Visit/Subsequent visit		Muscle cramps/twitching	(slider) 0-10	
First Visit/Subsequent visit		Excessive Saliva	(slider) 0-10	
First Visit/Subsequent visit		Constipation	(slider) 0-10	
First Visit/Subsequent visit		Disturbed sleep	(slider) 0-10	
First Visit/Subsequent visit		Shortness of breath	(slider) 0-10	
First Visit/Subsequent visit		Stiffness/ spasticity	(slider) 0-10	
First Visit/Subsequent visit		Choking sensation	(slider) 0-10	
First Visit/Subsequent visit		Depression	(slider) 0-10	
First Visit/Subsequent visit		Extreme/inappropriate emotions	(slider) 0-10	
First Visit/Subsequent visit	**Cognition**	**Does it seem that cognition is affected?**	**(radio)** **Yes | No**	
First Visit/Subsequent visit		Confirmation of dementia	radio) FTD (Frontotemporal Dementia) | Alzheimer's Dementia | Vascular Dementia | Parkinson's Disease + Dementia | Other, please state	
First Visit/Subsequent visit		Please state	text	

First Visit/Subsequent visit		ECAS (Edinburgh Cognitive and Behavioural ALS Screen) test administered?	(radio) Yes | No	
First Visit/Subsequent visit		ALS-Specific Score	Integer (number)	
First Visit/Subsequent visit		ALS-nonspecific	Integer (number)	
First Visit/Subsequent visit		Behavioural score	Integer (number)	
First Visit/Subsequent visit		Psychosis score	Integer (number)	
First Visit/Subsequent visit		Total score	Integer (number)	
First Visit/Subsequent visit		Other cognitive test administered?	text	
First Visit/Subsequent visit		Score	Integer (number)	
First Visit/Subsequent visit		Date administered	formatted date	
First Visit/Subsequent visit		Other cognitive test administered?	text	
First Visit/Subsequent visit		Score	Integer (number)	
First Visit/Subsequent visit		Date administered	formatted date	
First Visit/Subsequent visit	Treatment status	Riluzole	(radio) Yes | No	
First Visit/Subsequent visit		Riluzole Treatment commencement date	formatted date	
First Visit/Subsequent visit		Riluzole Treatment cessation Date	formatted date	
First Visit/Subsequent visit	Other treatment information	Tracheostomy	(radio) Yes | No	
First Visit/Subsequent visit		Date of Surgery	formatted date	
First Visit/Subsequent visit		Tracheostomy and ventilation	(radio) Yes | No	
First Visit/Subsequent visit		Date commenced	formatted date	
First Visit/Subsequent visit		Non-invasive ventilation	(radio) Yes | No	
First Visit/Subsequent visit		Date commenced	formatted date	
First Visit/Subsequent visit		NIV hours of use (Pt reported)	Float (number)	Added 7/7/23
First Visit/Subsequent visit	Respiratory Function Tests	Respiratory / Pulmonary Function Tests Done	(radio) Yes | No	
First Visit/Subsequent visit		Date performed	formatted date	
First Visit/Subsequent visit		Respiratory Test site	(drop down) This Health Service|Another service	Added 5/6/23
First Visit/Subsequent visit		FVC Predicted (%)	Integer (number)	
First Visit/Subsequent visit		FVC Litres (L)	Float (number)	

First Visit/Subsequent visit		SVC Predicted (%)	Integer (number)	
First Visit/Subsequent visit		SVC Litres (L)	Float (number)	
First Visit/Subsequent visit		SNIP	Integer (number)	
First Visit/Subsequent visit		MIP	Integer (number)	
First Visit/Subsequent visit		MEP	Integer (number)	
First Visit/Subsequent visit		Oxygen Saturation % (SpO2) on room air	Integer (number)	
First Visit/Subsequent visit	Sleep Tests	Sleep Study / Overnight Oximetry	(radio) Yes | No	
First Visit/Subsequent visit		Date of Sleep Study	formatted date	
First Visit/Subsequent visit		Date of Overnight Oximetry	formatted date	
First Visit/Subsequent visit	Medication (multiple entries)	Medications	text	
First Visit/Subsequent visit		Dose	Float (number)	
First Visit/Subsequent visit		Dose (unit of measure)	(drop down) ml | mg | microg | gram	
First Visit/Subsequent visit		Frequency	(drop down) daily | bd | tds | qid | hourly | two hourly | four hourly | prn	
First Visit/Subsequent visit		Administered via	(drop down) Oral | via PEG | Injection |Inhalation |Sublingual | Rectal | Topical	10/5/22
First Visit/Subsequent visit	Clinical trial information	Clinical trial participation	(radio) Yes | No	
First Visit/Subsequent visit	Clinical Trial details (multiple)	Name of Clinical Trial	text	
First Visit/Subsequent visit		Start date	formatted date	
First Visit/Subsequent visit		End date (if applicable)	formatted date	
First Visit/Subsequent visit	Other therapies or novel treatments	Other therapies or novel treatments?	(radio) Yes | No	
First Visit/Subsequent visit	Other therapy details	Describe other therapy	text	
First Visit/Subsequent visit		Start date	formatted date	
First Visit/Subsequent visit		End date (if applicable)	formatted date	

First Visit/Subsequent visit	Adaptive devices used at this time	Adaptive Devices Used	(checkbox) Ankle-foot Orthosis (AFO) | Cane | Walker/Frame | Wheelchair (occasional use, can walk independently) | Total dependency on wheelchair | Head or Neck Support | Communication Device | None | Other	
First Visit/Subsequent visit		Please Specify	text	
First Visit/Subsequent visit	Nutrition/ Feeding tube	Has a Feeding Tube been inserted?	(radio) Yes | No	
First Visit/Subsequent visit		If no, select the reason no feeding tube inserted	(checkbox) Not clinically indicated| Unable to be done| Under consideration by patient and family| Patient decided against| Patient consented, insertion scheduled or being scheduled| PEG insertion attempted but unsuccessful	Added 7/6/23
First Visit/Subsequent visit		Date of insertion	formatted date	

First Visit/Subsequent visit	Healthcare Professionals and services	Select Health Care Professionals and Services Currently Used	(checkbox) Is the patient a member of/involved with an MND Association? | MND Care Coordinator (MND Association Affiliated) | Physiotherapist | Respiratory/Sleep Physician | Palliative Care Physician | Research/Clinic Nurse for MND | Community/Home Nursing | Occupational Therapist | Speech Pathologist | Counsellor | Paid Attendant (for ADL's) | Home assessment/modification | Dietician | Social Worker | Has the patient used inpatient respite care in the past for MND? | Internet use for MND information | None | Other	
First Visit/Subsequent visit		Please Specify	text	
First Visit/Subsequent visit	VAD questions	Has VAD been raised by the patient?	(radio) Yes |No| Unknown	Added 7/7/23
First Visit/Subsequent visit		Was VAD discussed?	(radio) Yes |No| Unknown	Added 7/7/23
Subsequent visit	Inpatient Care(multiple)	Has there been an inpatient stay since last visit?	(radio) Yes | No	
Subsequent visit		Date of admission	formatted date	
Subsequent visit		Date of discharge	formatted date	
Subsequent visit		Reason for admission	(radio) Acute | Respite	
Completion	Registry Completion	Reason for Completion	(drop down) ALS Diagnoses Excluded | Patient Deceased | Lost to Follow-Up	
Completion		Date of Exclusion	formatted date	
Completion		Date of death	formatted date	
Completion		Date of last contact	formatted date	

Completion		From whom was this data obtained?	(drop down) Neurologist | Healthcare Professional | Relative or Caregiver | Other	
Completion		If Other, Specify	text	
Completion		Survivability	auto-calculated field	
Completion	If the patient is deceased please answer the following	Please confirm the diagnosis at the time of death	(radio) Undifferentiated| ALS- Bulbar Onset | ALS-Cervical Onset | ALS-Thoracic Diaphragmatic Onset | ALS-Lumbar Onset | Flail arm | Flail leg | PLS | ALS-FTD	
Completion		Mode of Death	(drop down) Respiratory | Cardiac | Suicide | Unknown | Other	
Completion		If Other, Specify	text	
Completion		And select one of:	(radio) Unexpected/Sudden Related to MND | Expected related to MND | Unexpected/Sudden Unrelated to MND	
Completion		Place of death	(drop down) Hospital (Pallitive Care) | Acute Hospital | Nursing Home | Home | Unknown | Other	
Completion		If Other, Specify	text	
Completion		In the two weeks leading to death, what medications were given?	(checkbox) Opiates | Benzodiazepines | Non-Steroidal Anti Inflammatories | Anticholinergics | Antidepressants | Unknown | No Drugs given | Other	
Completion		If Other, Specify	text	
Completion		In the two weeks leading to death, were any of these interventions initiated?	(checkbox) Oxygen | BiPap | Feeding Tube | Tracheostomy | None	
Completion		Date Oxygen commenced (if known)	formatted date	
Completion		Date BiPAP commenced (if known)	formatted date	
Completion		Date feeding tube inserted (if known)	formatted date	

Completion		Date Tracheostomy performed (if known)	formatted date	
Completion	Completion sign off	Comments	text	
Completion		MND Clinical Site	(drop down)	
Completion		Has the patient accessed information regarding Voluntary Assisted Dying (VAD)?	(radio) Yes | No |NA	
Completion		Did the patient utilise VAD?	(radio) Yes | No	
Completion		Investigator Name	text	
Completion		Investigator Signature	text	
Completion		Sign-Off Date	formatted date	