MiNDAUS Patient Reported Fields Data Dictionary

FORM_NAME	SECTION _NAME	CDE code	CDE_NAME	PVG VALUES/VARIABLE ENDSTATS	Change/ addition	Date
My Positioning (mndPositioning)	When I am in bed:	mndNeedUse	I need to use:	Neck support when sitting up, Bed cradle, Pressure relieving mattress, Extra pillows, An adjustable bed		
	When I am in bed:	mndLieFlat	I can lie flat	Yes, No		
	When I am in bed:	mndMove	I can move myself	Yes, No		
	When I am in bed:	mndNeedHelp	I need help to:	Change Position, Turn Over, Sit Up		
	When I am in bed:	mndNotes	I am more comfortable in bed when:	Text		
	When sitting, I can:	mndChairNeed	I need to use:	An electric wheelchair, Head or neck support, Pressure relief, A lift or electric recliner		
	When sitting, I can:	mndChairMove	Move myself in a chair	Yes, No		
	When sitting, I can:	mndChairNotes	I am more comfortable when seated if:	Text		
	My most comfortable position	mndComfyOther	Other (Please explain)	Text		
	My most comfortable position	myMostComfy	My most comfortable position is:	Other, In a comfortable chair (e.g. Recliner), In my wheelchair, In bed		

My Appointments (myAppointments)	List of Appointments	mndApptTime	Time			
	List of Appointments	mndAName	Name of Team Member	Text		
	List of Appointments	mndApptDate	Date of Appointment	Date		
My Breathing (myBreathing)	My Breathing	mndNIVUse	With NIV, I am:	Need full assistance, Need some assistance, Independent		
	My Breathing	mndBreathAssist	The following can help relieve my breathing difficulties:	Other, Positioning, A fan, Assisted cough techniques, Suctioning		
	My Breathing	mndBAOther	Other measures that can help:	Text		
	My Breathing	mndNIVYN	I use non-invasive ventilation (NIV):	Yes, No		
	My Breathing	mndNIVdur	In the last week, I've used NIV approximately X hours per day	Integer		
	My Breathing	mndNIVWhen	I use NIV	Most of the time, When needed, Whenever I sleep		
	My Breathing	mndBreathTracheostomy	I have a tracheostomy and need full breathing support at all times	Yes, No		
	My Breathing	mndBreathHard	I have breathing difficulties	Yes, No		
	My Breathing	mndWhenBreathHard	I have breathing difficulties when I am:	Moving a lot, Moving around, At rest		
My Care Team (myCareTeam)	Care Team Details	mndCName	Name:			

	Care Team Details	mndPrimary	Make this person my primary contact	Primary contact		
	Care Team Details	mndCEmail	Email:			
	Care Team Details	mndCPhone	Telephone:			
	Care Team Details	mndCRole	Role	Speech Pathologist (Swallowing), Speech Pathologist (Communication), Specialist Respiratory Nurse, Specialist Palliative Care Nurse, Specialist MND Nurse, Social Worker, Respiratory Physician, Research Nurse for MND, Psychologist, Psychiatrist, Physiotherapist, Physician,Palliative Care, Paid Carer, Occupational Therapist, Neurologist, MND Care Coordinator, MND Association Member, Gastroenterologist, Exercise Physiologist, Dietician, Counsellor, Community/Home Nurse, GP		
	Care Team Details	mndCAddress	Address:			
My Communication (myCommunication)	Communicating	mndComChairOther	Other (Please specify)			
	Communicating	mndComDifficulty	I have:	great difficulty communicating, some difficulty communicating, no difficulty communicating		

	Communicating	mndComTechOther	Additional information (Computer with switch)			
	Communicating	mndComTechs	I communicate using the following techniques or aids	Other, I use a computer operated by a switch ,I use an Eye Gaze device or computer, I use a voice amplifier, I use a communication board, I use a text to talk app on my smart phone or tablet, I write using paper, pen, boogie board, or Notes on my phone or device		
My eating and drinking needs (myEatDrink)	Needs: Eating and Drinking	mndEggs	Eggs (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndRed	Red Meat (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndWhite	White Meat (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndFish	Fish (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndAvoidOther	Other (Please Specify)			
	Needs: Eating and Drinking	mndOther	Other (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndFoodPrefer	I prefer the following foods, drinks or supplements:			

	Needs: Eating and Drinking	mndPEG	I use tube feeding (PEG):	Yes,No		
	Needs: Eating and Drinking	mndTube	I use tube feeding:	I need help with my tube feeds, I need tube feeding but enjoy small amounts of food by mouth, For all food and drink, To top up my meals, For hydration		
	Needs: Eating and Drinking	mndTubeDetails	Details of my tube feeding and preferred times of the day:			
	Needs: Eating and Drinking	mndSwallowD	I have swallowing difficulties	Yes,No		
	Needs: Eating and Drinking	mndByMouth	I can eat and drink by mouth	No, Some types, Yes		
	Needs: Eating and Drinking	mndHelpEat	I need help to eat and drink	I need to be fed, Some help, No		
	Needs: Eating and Drinking	mndACC	I use adapted cutlery and crockery	Yes, No		
	Needs: Eating and Drinking	mndFluids	I need my fluids at the following consistency	Level 4 - Extremely thick (Previously Level 900 (extremely thick, full thick or pudding) Level 3 - Moderately thick (Previously Level 400 (moderately thick) – Â½ thick or honey), Level 2 - Mildly thick (Previously Level 150 (mildly thick) Â¼ thick or nectar), Level 1 - Slightly thick, Level 0 - Thin (No thickening needed)		

	Needs: Eating and Drinking	mndFoodCon	I need my food at the following consistency:	Level 3 - Liquidised (equal to thickness of Level 3 liquid), Level 4 - Pureed (equal to thickness of level 4 liquid), Level 5 - Minced and moist, Level 6 - Soft and bite sized, Level 7 - Regular (normal food)		
	Needs: Eating and Drinking	mndAvoidFoods	I avoid the following foods:	Other, Fish, White Meat, Red Meat, Shellfish, Eggs, Peanuts, Dairy, Gluten, Soy		
	Needs: Eating and Drinking	mndGluten	Gluten (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndDairy	Dairy (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndPeanuts	Peanuts (Reason):	Lifestyle Choice Intolerance, Allergy		
	Needs: Eating and Drinking	mndSoy	Soy (Reason):	Lifestyle Choice, Intolerance, Allergy		
	Needs: Eating and Drinking	mndShell	Shellfish (Reason):	Lifestyle Choice, Intolerance, Allergy		
My Emotions (myEmotions)	My Emotions and Behaviour	mndEmotionNotes	My emotions and behaviour			

My ESS (myESS)	Situation	mndESSTraffic	In a car, stopped for a few minutes in traffic	3. High chance of dozing, 2 - Moderate chance of dozing, 1 - Slight chance of dozing, 0. Would never doze		
	Situation	mndESSSit	Sitting and reading	3. High chance of dozing, 2 - Moderate chance of dozing, 1 - Slight chance of dozing, 0. Would never doze		
	Situation	mndESSTV	Watching television	3. High chance of dozing, 2 - Moderate chance of dozing, 1 - Slight chance of dozing, 0. Would never doze		
	Situation	mndESSPublic	Sitting inactive in a public place (ie, Drs, meeting, cinema)	3. High chance of dozing, 2 - Moderate chance of dozing, 1 - Slight chance of dozing, 0. Would never doze		
	Situation	mndESSPassenger	As a passenger in a care for an hour without a break	3. High chance of dozing, 2 - Moderate chance of dozing, 1 - Slight chance of dozing, 0. Would never doze		
	Situation	mndESSLying	Lying down in the afternoon-circumstances permitting	3. High chance of dozing, 2 - Moderate chance of dozing, 1 - Slight chance of dozing, 0. Would never doze		
	Situation	mndESSSitNTalk	Sitting and talking to someone	3. High chance of dozing, 2 - Moderate chance of dozing, 1 - Slight chance of dozing, 0. Would never doze		
	Situation	mndESSSitNoDrink	Sitting quietly after a lunch without alcohol	3. High chance of dozing, 2 - Moderate chance of dozing,		

				1 - Slight chance of dozing, 0. Would never doze		
	My ESS Score:	mndESSScore	My ESS Score:	Calculated field integer		
My ALS-FRS Calculator		ALSFRS-R Calculator	Speech	(drop down) 0 | 1 |2 | 3 | 4		
			Salivation	(drop down) 0 | 1 |2 | 3 | 4		
			Swallowing	(drop down) 0 | 1 |2 | 3 | 4		
			Handwriting	(drop down) 0 | 1 |2 | 3 | 4		
			Do you have Gastrostomy / PEG?	(drop down) 0 | 1 |2 | 3 | 4		
			Cutting Food and Handling Utensils	(drop down) 0 | 1 |2 | 3 | 4		
			Cutting Food and Handling Utensils	(drop down) 0 | 1 |2 | 3 | 4		
			Dressing and Hygiene	(drop down) 0 | 1 |2 | 3 | 4		
			Turning Bed and adjusting Bed clothes	(drop down) 0 | 1 |2 | 3 | 4		
			Walking	(drop down) 0 | 1 |2 | 3 | 4		
			Climbing Stairs	(drop down) 0 | 1 |2 | 3 | 4		
			Difficulty of Breathing	(drop down) 0 | 1 |2 | 3 | 4		
			Difficulty of breathing when lying flat	(drop down) 0 | 1 |2 | 3 | 4		

			Respiratory Insufficiency	(drop down) 0 | 1 |2 | 3 | 4		
		ALSFRS-R Score	My ALSFRS Score	auto-calculated field		
My Legal Docs (myLegalDocs)	Legal Documents	legalDocUpload	Upload your legal files			
	Legal Documents	mndDocLocation	These documents are kept:	Text		
	Legal Documents	mndLDocs	I have any of the following documents	I have organ and/or tissue donation forms, I have completed a Do Not Resuscitate (DNR) Form, An Anticipatory Direction, A Medical Power of Attorney, An Enduring Power of Guardianship Other Other	10/5/22	'Other' field x 2
	Legal Documents	mndACD	I have an Advanced Care Directive (ACD)	Yes, No		
My Mouth Care and Saliva Management (myMCare)	Mouth Care and Saliva Management	mndMHelp	I need help with mouth care:	Yes, No		
	Mouth Care and Saliva Management	mndSalivaOther	Other (Please Specify)	Text		
	Mouth Care and Saliva Management	mndBrush	I like to brush my teeth:	Three times a day, Twice daily, Once a day		
	Mouth Care and Saliva Management	mndSwabs	I use mouth swabs in addition:	Yes, No		
	Mouth Care and Saliva Management	mndXSaliva	I have excessive saliva:	No, Sometimes, Always		

	Mouth Care and Saliva Management	mndManageSaliva	I manage excessive saliva with the following:	Other, Wiping Mouth, Clearance Techniques, Swallowing, Clothing Protection, Suction, Medication		
My Medical History (myMedHistory)	My medical / psychiatric conditions:	mndCondOther	Other (Please add below):	Text		
	My medical / psychiatric conditions:	mndConditions	Medical / Psychiatric Conditions that I have been diagnosed with:	Other, High Blood Pressure, Anxiety, Heart Disease, Diabetes, Depression, Cancer, Asthma		
My Medications and Allergies (myMedsNAll)	My Allergies	mndAllergies	My Allergies	Text		
	Medicines I Take	mndMedTime6Plus	Please specify the times you take your medication			
	Medicines I Take	mndMedAdmin	I take it as follows:	Injection - Intramuscular, Injection - Subcutaneous, Via Patch, Injection - Intravenous, Via Nebuliser, Via puffer Under Tongue (Sublingual), Via PEG, Via Mouth	Added 'Via puffer'	7/10/21
	Medicines I Take	mndMedTime6	Time 6			
	Medicines I Take	mndMedTime5	Time 5			
	Medicines I Take	mndMedTime4	Time 4			
	Medicines I Take	mndMedTime3	Time 3			

	Medicines I Take	mndMedTime2	Time 2			
	Medicines I Take	mndMedTime	Time 1			
	Medicines I Take	mndMedOther	Other			
	Medicines I Take	mndMedFreq	How frequently do you take it?	Other, Daily, Twice a Day, Every 12 Hours, Three Times Daily, Every 8 Hours, Four Times Daily, Every 6 Hours, Every 4 Hours, Every 2 Hours, Every Hour, Whenever Needed		
	Medicines I Take	mndMedPurpose	What it is for:	Text		
	Medicines I Take	mndMedDose	Dose	Integer		
	Medicines I Take	mndMedName	Medicine Name	MIMS/ Text		
	Medicines I Take	mndDateStarted	Date started	Date		
My Personal Care (myPC)	I need help with:	mndPHygiene	Personal Hygiene	Some, No, Yes		
	I need help with:	mndCareNeeds	The following things are important to me when being given personal care:	Text		
	I need help with:	mndShower	Showering:	Some, No, Yes		
	I need help with:	mndDress	Dressing and Hygeine	4. Normal Function, 3. Independent and complete self-care with effort or decreased efficiency, 2. Intermittent assistance or substitute methods, 1. Needs attendant for self-care, 0. Total Dependence		

	I need help with:	mndToil	Toileting:	Some, No, Yes		
My Physical Abilities (myPhysical)	Physical Abilities	mndWeakness	I have weakness in my:	Trunk, Head/Neck, Lower Limbs, Upper Limbs		
	Physical Abilities	mndRestNeeded	I need rest when:	Text		
	Physical Abilities	mndTaskAids	I use the following equipment to do things:	Text		
	Physical Abilities	mndMoveAids	I use the following equipment to move around:	Text		
	Physical Abilities	mndTransHelp	I need help to transfer to:	Toilet, A Chair, Bed, Not Needed		
	Physical Abilities	mndWalking	I can walk:	With Support or Aids, No, Yes		
	Physical Abilities	mndPhyUse	I use:	Head/Neck Support, Leg/Foot Splints, Arm/Wrist Splints		
My symptoms (mySymptoms)	Symptoms	mndDisSleep	Disturbed Sleep	Integer between 0-10		
	Symptoms	mndBreath	Shortness of breath	Integer between 0-10		
	Symptoms	mndSpasticity	Stiffness/spasticity	Integer between 0-10		
	Symptoms	mndChoking	Choking sensation	Integer between 0-10		
	Symptoms	mndDepression	Depression	Integer between 0-10		
	Symptoms	mndEmotion	Extreme/inappropriate emotions	Integer between 0-10		
	Symptoms	mndSymptomDate	Date completed:	Integer between 0-10		
	Symptoms	mndFatigue	Fatigue:	Integer between 0-10		

	Symptoms	mndPain	Pain:	Integer between 0-10		
	Symptoms	mndMuscle	Muscle Cramps/twitching	Integer between 0-10		
	Symptoms	mndSaliva	Excessive saliva	Integer between 0-10		
	Symptoms	mndConstipation	Constipation	Integer between 0-10		
External Specialist Visit (myspecialistVisitForms)	External Specialist Visit- First Visit (externalVisitFirstSec)	extVisitName	Please enter the name of the Specialist you saw	Text		
		extVisitContact	Email address of your contact person	Text		
		formUploadDate	Date form uploaded	Date		
		uploadedForm				
	External Specialist Visit- subsequent Visit (externalVisitSubSec)	extVisitName	Please enter the name of the Specialist you saw	Text		
		extVisitContact	Email address of your contact person	Text		
		formUploadDate	Date form uploaded	Date		
		uploadedForm				