

**UK MS Register: Main Instruments Data  
Dictionary  
Participant Portal**



**Version 2.1**

**MS Register Clinical Dataset  
Data Dictionary**

**14/01/2020**



Swansea University  
Prifysgol Abertawe



## UK MS Register Data Dictionary (CLINICAL)

### **1. Change Log 3**

*1.1 Change List: 4*

### **2. Table demographics – One row per Patient 5**

### **3. Table first\_visit : First Visit table. One row per patient 8**

## 1. Change Log

Version	Changes	Made By	Date
2.0	Created modern data dictionary from existing Redcap items	R Middleton	21/11/2019
2.1	Added additional previous dmt fields to first visit table	R Middleton	14/01/2020

### 1.1 Change List:

#### V2.1 Explicit changes

15/01/2020 Added Multiple previous DMT's to first visit form:

- fv\_more\_dmt\_yn
- fv\_additional\_dmts
- fv\_previous\_dmt\_comp\_2
- fv\_previous\_dmt\_stopped\_2
- fv\_prev\_dmt\_stopped\_reason\_2
- fv\_date\_prev\_dmt\_stop\_2
- fv\_previous\_dmt\_comp\_3
- fv\_previous\_dmt\_stopped\_3
- fv\_prev\_dmt\_stopped\_reason\_3
- fv\_date\_prev\_dmt\_stop\_3
- fv\_previous\_dmt\_comp\_4
- fv\_previous\_dmt\_stopped\_4
- fv\_prev\_dmt\_stopped\_reason\_4
- fv\_date\_prev\_dmt\_stop\_4
- fv\_previous\_dmt\_comp\_5
- fv\_previous\_dmt\_stopped\_5
- fv\_prev\_dmt\_stopped\_reason\_5
- fv\_date\_prev\_dmt\_stop\_5

These fields only available from this date  
Change

## 2. Table demographics – One row per Patient

Variable	Field Label	Description	Type	Values
<b>record_id</b>	Record ID	Unique patient identifier	text	Not released to external researchers
<b>demo_register_identifier</b>	Register ID	MS Register Study ID	text	Not released to external researchers
<b>demo_other_study_id</b>	Enter another study ID number	Yes if on another study no if not	yesno	0, No 1, Yes
<b>demo_other_study</b>	Other Study:	If patient enrolled on another study then this data can be entered	Integer	0, Swansea Biobank No 1, SWIMS 99, Other  Not released to external researchers
<b>demo_study_not_stated</b>	Study Not Stated in drop down	Free text field to name study	text	Not released to external researchers
<b>demo_other_study_no</b>	Other Study Id Number:	ID Number of that other study	text	Not released to external researchers
<b>participant_status</b>	Patient Status	Patients current status	integer	0, Active 1, Withdrawn from Study 2, Deceased
<b>date_of_death</b>	Date of Death  (approximation if not exactly known)	If patient has status of deceased then the date of death must be completed.	date	DD-MM-YYYY

Variable	Field Label	Description	Type	Values
<b>cause_of_death</b>	Cause of death:  (if known)	Free text for cause of death, only available if participant_status = deceased is selected	notes	Free text for entry of data.
<b>date_withdrawn</b>	Date withdrawn from study  (approximation if not exactly known)	Date patient withdrew from the study. Typically they have revoked consent	text	DD-MM-YYYY  Would not be deployed to researchers
<b>demo_date_enrolled</b>	Date subject signed consent	Date patient signed consent form to join the study.	text	DD-MM-YYYY
<b>demo_upload_3_2</b>	Signed Consent Form	Attached consent form as pdf	file	PDF (NOT ACCESSIBLE TO EXTERNAL RESEARCHERS)
<b>demo_nhs_number</b>	NHS Number	Patients NHS Number	text	NOT ACCESSIBLE TO EXTERNAL RESEARCHERS)
<b>demo_forename</b>	Forename	Patients Forename	text	NOT ACCESSIBLE TO EXTERNAL RESEARCHERS)
<b>demo_surname</b>	Surname	Patients Surname	text	NOT ACCESSIBLE TO EXTERNAL RESEARCHERS)
<b>demo_birth_date</b>	Date of Birth	Patients date of birth	text	DD-MM-YYYY, transformed to a year(IE 34) only prior to analysis. For anonymisation
<b>demo_gender</b>	Gender	Patients gender	Integer	0, Female 1, Male

Variable	Field Label	Description	Type	Values
				9, Not Stated
<b>demo_postcode</b>	Postcode	Participants postcode	text	Most commonly transformed to Lower Super Output area for anonymisation prior to research
<b>demo_email</b>	Email Address	Participants email	text	NOT ACCESSIBLE TO EXTERNAL RESEARCHERS
<b>demo_contact_tel</b>	Contact Phone Number	Participants mobile phone/ contact number	text	NOT ACCESSIBLE TO EXTERNAL RESEARCHERS
<b>demo_onset_date</b>	Onset Date	Patients disease onset date	text	DD-MM-YYYY, normally a best 'estimate' by the clinical staff entering the data. Generally released to researchers as YYYY only
<b>demo_date_diagnosis</b>	Diagnosis Date	Patients date of diagnosis	text	DD-MM-YYYY. Generally released to researchers as YYYY only
<b>demo_ms_type_at_diagnosis</b>	MS Type at Diagnosis	Patients disease type at diagnosis	integer	1, Relapsing Remitting 2, Primary Progressive 3, Secondary Progressive 4, Benign 9, Other
<b>demo_timestamp</b>	Demo Timestamp	Timestamp the record was last accessed	text	Not released to researchers

3. Table **first\_visit** : First Visit table. One row per patient



Column name	details	Type	Values
fv_mstype_visit	Patients MS Type at first visit – to determine is status has changes since diagnosis	integer	1, Relapsing Remitting 2, Primary Progressive 3, Secondary Progressive 4, Benign 9, Other
fv_date_conversion_sp	If 3 (spms) is selected in the fv_mstype_visit column then a date must be entered here	text	DD-MM-YYYY for SPMS progression
fv_relapses_last_year	Has the patient had any relapses in the last year	integer	0, No 1, Yes
fv_number_of_relapses	If fv_relapses_last_year = 1 then number of relapses must be entered	integer	0..20 is allowed
fv_most_severe_relapse	If fv_number_of_relapses >0 then the status of the most severe relapse must be selected	integer	1, Mild Impairment 2, Moderate Impairment 3, Severe Impairment
fv_edss_performed	Was an EDSS performed at visit, Yes or no	integer	0, No 1, Yes
fv_latest_edss	If fv_edss_performed =1 then enter the EDSS score of the patient	float	0-10
fv_walking_tests_done	Were walking tests performed at visit yes or no	integer	0, No 1, Yes
fv_walking_time	If fv_walking_tests_done = 1 then Time taken for the patient to walk 10m in seconds	integer	
fv_walking_method	If fv_walking_tests_done = 1 then What method was used to assess this	integer	1, Self Estimated 2, Trundle Wheel 3, Treadmill
fv_active_dmt_treatment	Is the patient currently receiving an active Disease Modifying Therapy	integer	0, No 1, Yes

fv_current_dmt	If fv_active_dmt_treatment = 1 then Select current DMT	integer	1, Alemtuzumab 2, Avonex 3, Betaferon 4, Copaxone 5, Fingolimod 6, Mitoxantrone 7, Natalizumab 8, Rebif 9, Teriflunomide 10, Tecfidera 11, Extavia 12, Plegridy 13, Fampyra 14, Ocrelizumab 15, Cladribine 16, Stem Cell Treatment 99, Other
fv_dmt_other	If fv_current_dmt = 99 (not stated) then note that here	text	Free text for Other dmt
fv_date_curr_dmt_started	If fv_active_dmt_treatment = 1 then Enter the date that is was started	text	dd-mm-yyyy of current dmt treatment
fv_previous_dmt	Was the patient on a DMT prior to this one yes or no	yesno	0, No 1, Yes

fv_previous_dmt_comp	If fv_previous_dmt = 1 then what was the compound	dropdown	1, Alemtuzumab 2, Avonex 3, Betaferon 4, Copaxone 5, Fingolimod 6, Mitoxantrone 7, Natalizumab 8, Rebif 9, Teriflunomide 10, Tecfidera 11, Extavia 12, Plegridy 13, Fampyra 14, Ocrelizumab 15, Cladribine 16, Stem Cell Treatment
fv_previous_dmt_stopped	Why was this previous DMT stopped, please select a reason	dropdown	1, Lack of efficacy 2, Side Effects 3, Other
fv_prev_dmt_stopped_reason	If fv_previous_dmt_stopped = 3 then please note reason the DMT was stopped	text	Free text
fv_date_prev_dmt_stop	If fv_previous_dmt = 1 then note the date that the DMT was stopped	text	DD-MM-YYYY the DMT was stopped
fv_more_dmt_yn	NOTE ONLY AVAILBLE > 14/01/2020 Add more previous DMT's?	yesno	0, No 1, Yes

fv_additional_dmts	<p>IF fv_more_dmt_yn = 1 then: How many more previous DMTs?</p> <p>Number selected here results in the number of previous DMT fields below being shown to the user.</p>	checkbox	<p>1, 1 2, 2 3, 3 4, 4</p>
fv_previous_dmt_comp_2	<p>If fv_additional_dmts = 1 then what was the compound</p>	dropdown	<p>1, Alemtuzumab 2, Avonex 3, Betaferon 4, Copaxone 5, Fingolimod 6, Mitoxantrone 7, Natalizumab 8, Rebif 9, Teriflunomide 10, Tecfidera 11, Extavia 12, Plegridy 13, Fampyra 14, Ocrelizumab 15, Cladribine 16, Stem Cell Treatment</p>
fv_previous_dmt_stopped_2	<p>If fv_additional_dmts = 1 then Why was this previous DMT stopped, please select a reason</p>	dropdown	<p>1, Lack of efficacy 2, Side Effects 3, Other</p>
fv_prev_dmt_stopped_reason_2	<p>If fv_previous_dmt_stopped_2 = 3 then enter free text</p>	text	Free text
fv_date_prev_dmt_stop_2	<p>If fv_additional_dmts = 1 then enter date that this was stopped</p>	date	dmy

fv_previous_dmt_comp_3	If fv_additional_dmts = 2 then what was the compound	dropdown	1, Alemtuzumab 2, Avonex 3, Betaferon 4, Copaxone 5, Fingolimod 6, Mitoxantrone 7, Natalizumab 8, Rebif 9, Teriflunomide 10, Tecfidera 11, Extavia 12, Plegridy 13, Fampyra 14, Ocrelizumab 15, Cladribine 16, Stem Cell Treatment
fv_previous_dmt_stopped_3	If fv_additional_dmts = 2 then Why was this previous DMT stopped, please select a reason	dropdown	1, Lack of efficacy 2, Side Effects 3, Other
fv_prev_dmt_stopped_reason_3	If fv_previous_dmt_stopped_23= 3 then enter free text	text	Free text
fv_date_prev_dmt_stop_3	If fv_additional_dmts = 2 then enter date that this was stopped	date	dmy

fv_previous_dmt_comp_4	If fv_additional_dmts = 3 then what was the compound	dropdown	1, Alemtuzumab 2, Avonex 3, Betaferon 4, Copaxone 5, Fingolimod 6, Mitoxantrone 7, Natalizumab 8, Rebif 9, Teriflunomide 10, Tecfidera 11, Extavia 12, Plegridy 13, Fampyra 14, Ocrelizumab 15, Cladribine 16, Stem Cell Treatment
fv_previous_dmt_stopped_4	If fv_additional_dmts = 3 then Why was this previous DMT stopped, please select a reason	dropdown	1, Lack of efficacy 2, Side Effects 3, Other
fv_prev_dmt_stopped_reason_4	If fv_previous_dmt_stopped_4 = 3 then enter free text	text	Free text
fv_date_prev_dmt_stop_4	If fv_additional_dmts = 3 then enter date that this was stopped	date	dmy

fv_previous_dmt_comp_5	If fv_additional_dmts = 4 then what was the compound	dropdown	1, Alemtuzumab 2, Avonex 3, Betaferon 4, Copaxone 5, Fingolimod 6, Mitoxantrone 7, Natalizumab 8, Rebif 9, Teriflunomide 10, Tecfidera 11, Extavia 12, Plegridy 13, Fampyra 14, Ocrelizumab 15, Cladribine 16, Stem Cell Treatment
fv_previous_dmt_stopped_5	If fv_additional_dmts = 4 then Why was this previous DMT stopped, please select a reason	dropdown	1, Lack of efficacy 2, Side Effects 3, Other
fv_prev_dmt_stopped_reason_5	If fv_previous_dmt_stopped_5 = 3 then enter free text	text	Free text
fv_date_prev_dmt_stop_5	If fv_additional_dmts = 4 then enter date that this was stopped	date	dmy
fv_participant_pregnant	Is the participant currently pregnant, only displayed if the patient has demo_gender = 0	yesno	0, No 1, Yes
fv_smoker	Does the patient indicate that they are current smoker	yesno	0, No 1, Yes
fv_no_smoked_daily	If fv_smoker = 1 then indicate how many cigarettes are smoked daily	Integer	Number of cigarettes smoked daily
fv_smoked_since	If fv_smoker = 1 then when did the patient start smoking	text	DD-MM-YYYY that the patient started smoking.

fv_onset_localisation	When first MS symptoms were first observed, what systems did they primarily effect?	Integer	1, Spinal 2, Visual 3, Cortex 4, Cerebellar/Brain Stem
fv_onset_symptoms	When onset symptoms were experienced. What specifically were they, multiple answers are possible	integer	1, Vision 2, Co-ordination 3, Cognitive 4, Motor 5, Bladder Bowel 6, Encephalopathy 7, Fatigue 8, Sensory 9, Other
fv_onset_symptoms_other	If fv_onset_symptoms = 9 then state what the symptoms were as plain text	text	Text of what other symptoms were experienced
fv_timestamp	Auto generated timestamp of date entered	text	DD-MM-YYYY HH:MM:SS  NOT ACCESSIBLE TO EXTERNAL RESEARCHERS