

UK MS Register: Main Instruments Data Dictionary Participant Portal



Version 2

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1. Revision History

Version	Date	Comment	Author
1	01/08/2018	Initial version of UKMS Data dictionary. Redcap produced data dictionary	Rod Middleton
2	21/11/19	Customised and specific data dictionary for version 3 of the UK MS Register.	Rod Middleton

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3. Purpose and Background

The purpose of this document is to state all data items captured for the Participant portal of the United Kingdom MS Register. Specifically for version 3 of the platform. Accessible to end users at:

<https://ukmsregister.org/>

Launched to limited test users in July 2018, formal launch data September 2018

Some data are ported from versions 1 & 2 where appropriate. Start dates are listed and alterations noted where appropriate

To register for a test account and assess in situ as a researcher visit :

<https://demov3.ukmsregister.org/>

Create an account and answer questionnaires.

There is a clinical data dictionary version of this document.

4. Instruments in this document

Instrument Name	Format	Purpose	Data collected for
Demographics	Single Point	Basic participant identifiers	MS Register/All researchers
About Me	Single Point	Household/Educational data	MS Register/All researchers
MyMS	Single Point	Specific MS Epidemiology	MS Register/All researchers
EQ5D-3L	Longitudinal	General QOL Instrument	MS Register/All researchers
HADS	Longitudinal	General Anxiety/Depression instrument	MS Register/All researchers
FSS	Longitudinal	General Fatigue Instrument	MS Register/All researchers
MSIS29V1/2	Longitudinal	MS Specific Impact scale	MS Register/All researchers
MSWS-12	Longitudinal	MS Specific walking scale	MS Register/All researchers
WebEDSS	Longitudinal	MS Specific outcome measure	MS Register/All researchers
Comorbidity	Longitudinal	Other associated conditions	MS Register/All researchers
Symptoms	Longitudinal	Current symptoms and severity	MS Register/All researchers
Relapses	Longitudinal	Any relapses in the last six months	MS Register/All researchers

4.1 Supplemental Instruments

Instruments collected by other researchers are available in supplemental documents. These are available on request and for data, with permission from that researcher. These are only a top-level overview of the studies. Studies may contain multiple instruments.

Instrument Name	Format	Purpose	Data collected for
PROMIS Fatigue	Longitudinal	Pharmaceutical Study	Merck KgAA
Costs of MS	Single Point	Pharmaceutical Study	Sanofi Genzyme
Vitamin D and MS	Single Point	Epidemiology	Queen Mary University London
My MS My Needs	Longitudinal	Population survey	MS Society UK
MS Childbirth	Single Point	Population Survey	Queen Mary University London/MS Register
MS Film	Single Point	Population Survey	Imperial College London
Illness Events	Longitudinal	Population Survey	Exeter University

4.2 Portal demographics – One row per Participant

Participants once signed up must enter demographic data at Registration. Since V3 email addresses are validated. Periodically participants are prompted to update this data (18 monthly), there are visual cues on the Hub screen that will prompt users to update data on login if it looks incorrect or circumstances have changed.

Data derived from : Other MS Registers, Clinical Advisory Group, PwMS, Standardised data dictionaries

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
YearOfBirth	Year of Birth	Participants year of birth	Int	4	Year of birth extracted from participants whole date of birth
Gender	Gender	Participants gender Single choice checkbox	Int	1	1, Male 2, Female 3, Prefer not to say
Ethnicity	Ethnicity	Participants self-declared ethnicity Based on NHS UK Ethnicity lists Single choice checkbox	Int	2	1, I am white (British, Irish, Other) 2, I am mixed (White and Black Caribbean, Black 3, I am Black or Black British (Caribbean, African, Other) 4, Other (Chinese, Another ethnic group) 5, I am Asian or British Asian (Indian / Pakistani / Bangladeshi) 6, I would rather not say 7, British 8, Irish 9, Other 10, White and Black Caribbean 11, White and Black African 12, White and Asian

Variable	Field Label	Description	Type	Length	Values
					13, Other 14, Caribbean 15, African 16, Other 17, Chinese 19, Another ethnic group 20, Indian 21, Pakistani 22, Bangladeshi 23, Any other Asian background

4.3 Table About Me: One row per participant

Deeper epidemiological data, typically only the most recent update is made available to researchers. Periodically participants are prompted to update this data (18 monthly), there are visual cues on the Hub screen that will prompt users to update data on login if it looks incorrect or circumstances have changed

Data derived from: Other MS Registers, Clinical Advisory Group, PwMS, Standardised data dictionaries

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
v3_height_weight	Do you know your height and weight?	Question to ask patient if they know their height and weight	Int	1	0, No 1, Yes
v3_height_m	Height in Meters	Enter Height in M	Int	1	Only entered if v3_height_weight = 1 Bounds 0 to 5
v3_weight_kg	Weight in Kilograms	Enter weight in kg	Int	4	Only entered if v3_height_weight = 1 Bounds 0 to 1000
v3_smoking	Have you ever smoked tobacco?	Has the participant ever smoked tobacco, enter 'yes' to proceed	Int	1	0, No 1, Yes
v3_smoking_year_start	What year did you start smoking?	Enter the year you started smoking	Int	4	Only entered if v3_smoking = 1 Bounds 1920 - 9999

Variable	Field Label	Description	Type	Length	Values
v3_smoking_no	How many per day?	How many cigarettes smoked per day	Int	3	Only entered if v3_smoking = 1 Bounds 1 - 200
v3_smoking_still	Do you still smoke?	Does the patient still smoke?	Int	1	0, No 1, Yes
v3_smoking_gave_up	When did you give up?	If the patient gave up, when did they give up? If unsure of exact date enter 01/01/YYYY	date	8	If v3_smoking_still = 0 dd/mm/yyyy
v3_vaping	Have you ever vaped?	Has the patient ever used a vape	Int	1	0, No 1, Yes
v3_vaping_year_start	What year did you start vaping?	Enter year started vaping	year	4	If v3_vaping = 1 Bounds 1920 - 9999
v3_vaping_flavour	What flavour(s) did/do you vape?	Free text field to allow participant to define flavour of vape	notes	2000	If v3_vaping = 1 Then enter a flavour narrative
v3_vaping_strength	What strengths did/do	What strength of vape do you use as a drop down list	int	1	If v3_vaping = 1 0, 0mg or 0% (Nicotine Free)

Variable	Field Label	Description	Type	Length	Values
	you vape?				1, 3mg or 0.3% 2, 6mg or 0.6% 3, 8mg or 0.8% 4, 10mg or 1% 5, 12mg or 1.2% 6, 16mg or 1.6% 7, 18mg or 1.8% 8, More than 18mg
v3_vape_ml	How many ml per week did/do you Vape on average?	How many mls per week are vaped on average, drop down list	Int	1	If v3_vaping = 1 0, Less than 10ml 1, 10 ml 2, 20 ml 3, 30 ml 4, 40 ml 5, 50, ml 6, More than 50 ml
v3_vape_still	Do you still vape?	Do you still vape now, yes or no?	Int	1	If v3_vaping = 1 0, No 1, Yes
v3_vape_year_stop	What year did you stop vaping?	If the patient does not vape currently when did they stop?	year	4	If v3_vape_still = 0 Bounds 1920 - 2099
v3_cannabis	Have you taken cannabis to	Has the patient used any cannabis to manage their condition.	Int	1	0, No 1, Yes

Variable	Field Label	Description	Type	Length	Values
	manage your MS?				
v3_education	What is your highest educational level?	Checkbox list to define Highest level of education. Only one can be selected	Int	1	0, Primary School 1, Secondary school 2, Occupational certificate or diploma 3, University bachelor's degree 4, University postgraduate degree 5, Other
v3_education_other	If other please define:	Free text to describe Other educational attainment	text	200	If v3_education= 5 then Free text to define highest educational achievement
v3_employment_status	Which of the following best describes your employment status?	Checkbox list to define current employment status	Int	1	0, Regular Paid Employment 1, Self-employed 2, Temporarily sick/disabled 3, Looking after my home/family 4, Engaged in voluntary work 5, Unemployed 6, In formal education 7, Retired 8, Permanently sick/disabled 9, Government Training Scheme 10, Not applicable 11, Other reasons not working:
v3_employment_status_other	If Other please define	Free text to describe Other employment status.	text	200	If v3_employment_status = 11 Enter free text
v3_employment_basis	Is this on a part time or	If employment is categorised as Regular, Self employed or in formal education seek more detail	radio	1	If v3_employment_status = 0 or 1 or 6 then 0, On a full time basis 1, On a part time basis

Variable	Field Label	Description	Type	Length	Values
	full time basis?:				
v3_no_hours_worked	How many hours a week do you work?	If patient is not working full time, how many hours do they work	Int	4	If v3_employment_basis = 1 Then enter hours worked
v3_employment_hours	In your employment, are you working the same number of hours per week as 12 months ago?	If patient is working Regular full time employment of Self employed is their working hours the same as 1 year ago Single choice checkbox	Int	1	If v3_employment_status = 0 or 1 then 0, Yes, about the same 1, No, I work more hours 2, No, I work less hours MAINLY because of my MS 3, No, I work less hours but NOT MAINLY because of my MS
v3_retired_reason	Which of the following best describes your reason for retiring?	If the patient has indicated that they are retired, then why did they retire Single choice checkbox	Int	1	If v3_employment_status = 7 then 0, Due to a medical condition 1, I have completed my career

Variable	Field Label	Description	Type	Length	Values
v3_seeking_employment	Are you seeking paid employment?	If the patient is Engaged in voluntary work or Unemployed are they seeking employment Single choice checkbox	Int	1	If v3_employment_status = 4 or 5 then 0, No 1, Yes
v3_occupation	Which of the following best describes your current/ most recent employment?	Choose the closest occupational category to your employment Single choice checkbox	Int	1	1, Managers, Directors and senior officials (e.g. Office, IT , Purchasing, Healthcare or other managers) 2, Professional Occupations (e.g. Chemists, Civil Engineers, Electronics Engineers, Dentists, Doctors, Nurses, Social Workers) 3, Associate professional and technical occupations (e.g. Nurses, Laboratory technicians, IT Support, Radiographers, Artists, Authors) 4, Administrative and secretarial occupations (e.g. Clerks, Secretaries, Personal Assistants, Receptionists) 5, Skilled/trade occupations (e.g. Farmers, Electricians, Industrial Operators, Plumbers, Mechanics, Aircraft Engineers, Painters) 6, Caring, leisure and other service occupations (e.g. Healthcare, Childcare, looking after animals, housekeeping and hairdressing) 7, Sales and customer service occupations (e.g. Sale and Retail assistants, Call centre workers, Debt collectors, Housekeepers) 8, Process plant and machine operatives(e.g. Machine Operators, Textile Process Operators, Electroplaters, Plant Workers) 9, Elementary occupations (e.g. Forestry Workers, Farm Workers, Labourers, Waitresses, Porters, Bar Staff, Shelf Filler, Traffic Wardens)

Variable	Field Label	Description	Type	Length	Values
v3_employ_ms_diag	Were you diagnosed MS before you started your current employment or during it?	If patient has selected 0, Regular Paid Employment Or Self-employed then were they already diagnosed with MS Single choice textbox	Int	1	If v3_employment_status = 0 or 1 0, I was diagnosed with MS before commencing my current employment 1, I was diagnosed with MS during the period of my current employment:
v3_employment_informed	Did you inform your employer that you have MS?	If the patient was diagnosed with MS prior to starting current employment, did you inform your them Single choice checkbox	Int	1	If v3_employ_ms_diag = 0 0, I informed my employer I had MS at the time of commencing employment or within four weeks of commencement 1, I informed my employer I had MS months/years after commencing employment 2, I have not yet informed my employer I have MS
v3_employment_mods	Have you required any modifications to your current working	If the patient had a diagnosis of MS prior to starting employment were any modifications made to the workplace Single choice checkbox	Int	1	If v3_employ_ms_diag = 0 0, No 1, Yes

Variable	Field Label	Description	Type	Length	Values
	role or environment because of your MS?				
v3_employment_change	Have you changed your employer or left employment in the last 12 months?	<p>If the patient had a diagnosis of MS prior to starting employment have you changed employment</p> <p>Single choice checkbox</p>	Int	1	<p>If v3_employ_ms_diag = 0</p> <p>0, No 1, Yes</p>
v3_employment_ms_inv	If Yes, was the fact that you have MS at all involved in your change of employer or leaving employment?	<p>If the patient had a diagnosis of MS prior to starting employment did this cause you to change employer</p> <p>Single choice checkbox</p>	Int	1	<p>If v3_employment_change = 1</p> <p>0, No 1, Yes</p>

Variable	Field Label	Description	Type	Length	Values
v3_household	Which of the following best describes your household:	Current household composition Single choice checkbox	Int	1	1, Single adult, 2, Single parent 3, Single adult pensioner 4, An adult married/couple 5, An adult married/couple that receives a pension 6, An adult household who are related e.g. brother and sister 7, An Adult household who are not related 8, A married/couple or family living with other relatives and/or unrelated adults 9, A married/couple who lives with other couples or families
v3_children	Which of the following best describes the status of the children in your household?	If the household has not explicitly excluded children in v3_household get the status Single choice checkbox	Int	1	If v3_household = 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 0, No Children 1, Dependent children 2, Non dependent children 3, Dependent children and non dependent children
v3_family	Do you have any direct relations with MS?	Any first degree family with a history of MS Single choice checkbox	Int	1	0, No 1, Yes

Variable	Field Label	Description	Type	Length	Values
v3_family_ms	What direct members of your family have MS?	Choose the family member that had a diagnosis of MS Single choice checkbox	Int	1	If v3_family = 1 then 0, Mother 1, Father 2, Brother 3, Sister 4, Son 5, Daughter

4.4 MyMS : One row per patient

Specific MS Questionnaire related to Diagnosis and any subsequent changes in diagnosis there are visual cues on the Hub screen that will prompt users to update data on login if it looks incorrect or circumstances have changed

Data derived from : Clinical Advisory Group, PwMS,

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
v3_remember_symptoms	Do you remember when your first MS symptoms occurred?	Remember onset date Y/N Single choice checkbox	Int	1	0, No 1, Yes
v3_symptoms_year	What year did you first start experiencing the symptoms of MS?	If onset date is remembered then enter a year In the format YYYY	Int	4	If v3_remember_symptoms = 1 YYYY Bounds 1950 -2050
v3_symptoms_month	What month did you first start	If onset date is remembered then enter a month Single choice checkbox	Int	2	If v3_remember_symptoms = 1 0, Don't remember 1, Jan 2, Feb

Variable	Field Label	Description	Type	Length	Values
	experiencing the symptoms of MS?				3, Mar 4, Apr 5, May 6, June 7, July 8, August 9, Sept 10, Oct 11, Nov 12, Dec
v3_symptoms_first	Do you remember what your first symptoms were? (You may select more than one)	If onset date remembered then choose onset symptoms Multiple choice checkbox	Int	1	If v3_remember_symptoms = 1 0, Don't Remember 1, Walking 2, Vision 3, Numbness
v3_remember_diag_date	Do you remember when you received a confirmed	Do you remember your diagnosis date Single choice checkbox	Int	1	0, No 1, Yes

Variable	Field Label	Description	Type	Length	Values
	diagnosis of MS?				
v3_yr_diagnosis	Year of diagnosis	If diagnosis year is remembered then enter a year In the format YYYY	Int	4	If v3_remember_diag_date = 1 YYYY Bounds 1950 -2050
v3_month_diagnosis	Month of Diagnosis	If onset date is remembered then enter a month Single choice checkbox	Int	2	If v3_remember_diag_date = 1 0, Don't remember 1, Jan 2, Feb 3, Mar 4, Apr 5, May 6, June 7, July 8, August 9, Sept 10, Oct 11, Nov 12, Dec
v3_ms_at_diagnosis	What type of MS were you diagnosed with?	Type of MS at diagnosis. Choices as decided by MS Register clinical advisory group Single choice checkbox	Int	1	0, Primary Progressive 1, Relapsing Remitting 2, Secondary Progressive 3, Don't know

Variable	Field Label	Description	Type	Length	Values
v3_diagnosis_test	What tests were carried out to confirm this diagnosis? (You can select more than one)	Test for diagnosis of MS Multiple choice checkbox	Int	1	0, Don't Remember 1, Clinical Findings 2, MRI 3, Lumbar Puncture
v3_pp_mstype_now	Type of MS now?	If PPMS as diagnosis, what MS type do you currently have? Single choice checkbox	Int	1	If [v3_ms_at_diagnosis] = '0' 0, Primary Progressive 3, Don't know
v3_rr_mstype_now	Type of MS now?	If RRMS as diagnosis, what MS type do you currently have? Single choice checkbox	Int	1	If [v3_ms_at_diagnosis] = '1' 1, Relapsing Remitting 2, Secondary Progressive 3, Don't know 4, Benign
v3_sp_mstype_now	Type of MS now?	If SPMS as diagnosis, what MS type do you currently have?	Int	1	If [v3_ms_at_diagnosis] = '2'

Variable	Field Label	Description	Type	Length	Values
		Single choice checkbox			2, Secondary Progressive 3, Don't know
v3_dk_mstype_now	Type of MS now?	If MS as diagnosis was unknown, what MS type do you currently have? Single choice checkbox	Int	1	If [v3_ms_at_diagnosis] = '3' 0, Primary Progressive 1, Relapsing Remitting 2, Secondary Progressive 3, Don't Know 4, Benign
ms_v3_myms_change	Can you remember what year that this change in diagnosis occurred?	Change in diagnosis status Single choice checkbox	Int	1	0, No 1, Yes
v3_mstype_now_date	What year were you diagnosed with this type of MS?	If year of change in diagnosis of MS Type is remembered then enter in YYYY Year text field	Int	4	If [ms_v3_myms_change] = '1' YYYY Bounds 1950 -2050
v3_mstype_now_month	What month were you	If change in diagnosis date is remembered then enter a month			0, Don't remember 1, Jan 2, Feb

Variable	Field Label	Description	Type	Length	Values
	diagnosed with this type of MS?	Single choice checkbox			3, Mar 4, Apr 5, May 6, June 7, July 8, August 9, Sept 10, Oct 11, Nov 12, Dec

4.5 EQ5D-3L : EuroQOL Longitudinal Data : Multiple scores possible for Individuals

The EQ5D is a general quality of life instrument that assesses participants overall quality of life, there are 6 dimensions. Five ask you to rate your quality of life on 3-point scale about activities of daily living. The sixth is a self-rated marker out of 100 for how you view your own quality of life right now.

Data Derived from: EuroQOL

Reference

Brooks R. EuroQol: the current state of play. Health Policy. 1996;37:53–72.

FIRST DATA : 12/05/2011

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
eq5d_1	Mobility	Participant supplied rating of mobility Single choice checkbox			0, I have no problems in walking about 1, I have some problems in walking about 2, I am confined to bed
eq5d_2	Self Care	Participant supplied rating of Self Care Single choice checkbox	Int	1	0, I have no problems with self-care 1, I have some problems washing or dressing myself 2, I am unable to wash or dress myself
eq5d_3	Usual Activities (e.g. work, study, housework, family)	Participant supplied rating of ability to carry out their everyday activities Single choice checkbox	Int	1	0, I have no problems with performing my usual activities 1, I have some problems with performing my usual activities 2, I am unable to perform my usual activities

	or leisure activities)				
eq5d_4	Pain/Discomfort	Participant supplied rating of pain Single choice checkbox	Int	1	0, I have no pain or discomfort 1, I have moderate pain or discomfort 2, I have extreme pain or discomfort
eq5d_5	Anxiety/Depression	Participant supplied rating of Anxiety and depression. NOTE this is not the HADS score. Single choice checkbox	Int	1	0, I am not anxious or depressed 1, I am moderately anxious or depressed 2, I am extremely anxious or depressed
eq5d_vas	EQ5D Visual Analogue Scale, please rate out of 100 how you see your quality of life at the moment	Participant rates them selves from 0...100 via mouse/tap on a scale of how they would rate their health right now. Single choice checkbox	Int	3	Visual analogue scale Bounds 0 – 100 0 = worst health imaginable 100 = Best health imaginable
CompletedDate	NA	Datestamp that the survey was completed	Date time	15	Timestamp YYYY-MM-DD HH:MM:SS

4.6 HADS :The Hospital Anxiety and Depression Scale (HADS). Longitudinal Data : Multiple scores possible for Individuals over time

Standardised questionnaire examining anxiety and depression , validated in pwMS

Data Derived from : <https://www.gi-assessment.co.uk/products/hospital-anxiety-and-depression-scale-hads/>

Reference : Zigmond, A, Snaith, R.P. The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica. 1983;67:361–370.

FIRST DATA : 12/05/2011

Questions are split into Anxiety and Depression

1,3,5,7,9,11,13 Are anxiety

2,4,6,8,10,12,14 are depression

0-7 On either scale is normal

8-10 Borderline

11-21 Abnormal

Variable	Field Label	Description	Type	Length	Values
Userld	Userld	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
v3_hads_q1	I feel tense or 'wound up':	Anxiety indicator	Int	1	3, Most of the time 2, A lot of the time 1, From time to time, occasionally 0, Not at all
v3_hads_q2	I still enjoy the things I used to enjoy:	Depression indicator	Int	1	0, Definitely as much 1, Not quite so much 2, Only a little 3, Hardly at all
v3_hads_q3	I get a sort of	Anxiety indicator	Int	1	3, Very definitely and quite badly 2, Yes, but not too badly

	frightened feeling like something awful is about to happen:				1, A little, but it doesn't worry me 0, Not at all
v3_hads_q4	I can laugh and see the funny side of things:	Depression indicator	Int	1	0, As much as I always could 1, Not quite as much now 2, Definitely not so much now 3, Not at all
v3_hads_q5	Worrying thoughts go through my mind:	Anxiety indicator	Int	1	3, Most of the time 2, A lot of times 1, From time to time 0, Only occasionally
v3_hads_q6	I feel cheerful:	Depression indicator	Int	1	0, Most of the time 1, Usually 2, Not often 3, Not at all
v3_hads_q7	I can sit at ease and feel relaxed	Anxiety indicator			0, Definitely 1, Usually 2, Not Often 3, Not at all
v3_hads_q8	I feel as if I am slowed down:	Depression indicator	Int	1	3, Nearly all of the time 2, Very often 1, From time to time 0, Not at all

v3_hads_q9	I get a sort of frightened feeling like 'butterflies in the stomach':	Anxiety indicator	Int	1	0, Not at all 1, From time to time 2, Quite often 3, Very often
v3_hads_q10	I have lost interest in my appearance:	Depression indicator	Int	1	3, Definitely 2, I don't take as much care as I should 1, I may not take quite as much care 0, I take just as much care as ever
v3_hads_q11	I feel restless as if I have to be on the move:	Anxiety indicator	Int	1	3, Very much indeed 2, Quite a lot 1, Not very much 0, Not at all
v3_hads_q12	I look forward with enjoyment to things:	Depression indicator	Int	1	0, As much as I ever did 1, A little less than I used to 2, Definitely less than I used to 3, Hardly at all
v3_hads_q13	I get sudden feelings of panic:	Anxiety indicator	Int	1	3, Very often indeed 2, Quite often 1, From time to time 0, Not at all

v3_hads_q14	I can enjoy a good book or radio or TV programme:	Depression indicator	Int	1	0, Often 1, Sometimes 2, Not often 3, Hardly at all
CompletedDate	NA	Datestamp that the survey was completed	Date time	15	Timestamp YYYY-MM-DD HH:MM:SS

4.7 Fatigue Severity Scale (FSS) : Longitudinal Data : Multiple scores possible for Individuals over time

FSS used to ascertain changes in fatigue over time, validated in pwMS

Data derived from Krupp LB. The Fatigue Severity Scale: Application to Patients With Multiple Sclerosis and Systemic Lupus Erythematosus. Arch Neurol. 1989;46:1121.

Details:

9 Item questionnaire with a maximum total of 63 and minimum of 9

Scores can be obtained by summing all values.

Scores of more than 36 are indicative of fatigue.

FIRST DATA : 15/09/2016

Alternative calculation method

in 2011, Lerdal found that it is not advisable to use items 1 and 2 in the FSS in a mean score. FSS-7 shows better validity and reliability. This questionnaire with 7 items is also more sensitive for measuring the change in fatigue

Field labels hold requisite data.

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
fss_1	My motivation is lower when I am fatigued.	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree
fss_2	Exercise brings on	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3

	my fatigue				4, 4 5, 5 6, 6 7, 7 - Strongly Agree
fss_3	I am easily fatigued	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree
fss_4	Fatigue interferes with my physical functioning.	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree
fss_5	Fatigue causes frequent problems for me	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree
fss_6	My fatigue prevents sustained physical	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree

	functioning				
fss_7	Fatigue interferes with carrying out certain duties and responsibilities	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree
fss_8	Fatigue is among my most disabling symptoms	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree
fss_9	Fatigue interferes with my work, family, or social life	Single item checkbox	Int	1	1, 1 - Strongly Disagree 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 - Strongly Agree
CompletedDate	NA	Datestamp that the survey was completed	Datetime	15	Timestamp YYYY-MM-DD HH:MM:SS

4.8 Multiple Sclerosis Impact Scale 29 V1 Longitudinal Data : Multiple scores possible for Individuals over time

MSIS was created by Hobart et al to be a more effective assessment of the impact of MS than EDSS score and other purely physical outcome measures. The MS Register has asked both version 1 and version 2 of the MSIS score.

DATA FROM

V1 FROM 12/05/2011 To 12/04/2012

V2 FROM 12/04/2012

Data derived from Hobart J. The Multiple Sclerosis Impact Scale (MSIS-29): A new patient-based outcome measure. Brain. 2001;124:962-973. Version 2 from direct communication with Hobart J

Asks for these impressions over the last **two** weeks. MS Specific Instrument of Impact separated into Physical and Psychological Components. First 20 questions are physical last 9 are psychological.

Data can be totalled as a complete score by addition, or viewed as Physical and Psychological sub scores.

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
msis29_v2_q1	Do physically demanding tasks?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q2	Grip things tightly (e.g. turning on taps)?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely

msis29_v2_q3	Carry things?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q4	Problems with your balance?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q5	Difficulties moving about indoors?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q6	Being clumsy?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q7	Stiffness?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q8	Heavy arms and/or legs?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q9	Tremor of your	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little

	arms or legs?				3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q10	Spasms in your limbs?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q11	Your body not doing what you want it to do?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q12	Having to depend on others to do things for you?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q13	Limitations in your social and leisure activities at home?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q14	Being stuck at home	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately

	more than you would like to be				4, Quite a bit 5, Extremely
msis29_v2_q15	Difficulties using your hands in everyday tasks?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q16	Having to cut down the amount of time you spent on work or other daily activities?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q17	Problems using transport (e.g. car, bus, train, taxi, etc.)?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely

msis29_v2_q18	Taking longer to do things?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q19	Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q20	Needing to go to the toilet urgently?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q21	Feeling unwell?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q22	Problems sleeping?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely

msis29_v2_q24	Worries related to your MS?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q23	Feeling mentally fatigued?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q25	Feeling anxious or tense?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q26	Feeling irritable, impatient, or short-tempered?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q27	Problems concentrating?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
msis29_v2_q28	Lack of confidence?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely

msis29_v2_q29	Feeling depressed?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Quite a bit 5, Extremely
CompletedDate	NA	Datestamp that the survey was completed	DateTime	15	Timestamp YYYY-MM-DD HH:MM:SS

4.9 Multiple Sclerosis Impact Scale 29 V2 Longitudinal Data : Multiple scores possible for Individuals over time

MSIS was created by Hobart et al to be a more effective assessment of the impact of MS than EDSS score and other purely physical outcome measures. The MS Register has asked both version 1 and version 2 of the MSIS score.

DATA FROM

V2 FROM 12/04/2012

Data derived from Hobart J. The Multiple Sclerosis Impact Scale (MSIS-29): A new patient-based outcome measure. Brain. 2001;124:962-973. Version 2 from direct communication with Hobart J

Asks for these impressions over the last **two** weeks. MS Specific Instrument of Impact separated into Physical and Psychological Components. First 20 questions are physical last 9 are psychological.

Data can be totalled as a complete score by addition, or viewed as Physical and Phycological sub scores.

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
msis29_v2_q1	Do physically demanding tasks?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q2	Grip things tightly (e.g. turning on taps)?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely

msis29_v2_q3	Carry things?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q4	Problems with your balance?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q5	Difficulties moving about indoors?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q6	Being clumsy?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q7	Stiffness?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q8	Heavy arms and/or legs?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q9	Tremor of your arms or legs?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q10	Spasms in your limbs?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely

msis29_v2_q11	Your body not doing what you want it to do?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q12	Having to depend on others to do things for you?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q13	Limitations in your social and leisure activities at home?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q14	Being stuck at home more than you would like to be	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q15	Difficulties using your hands in	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely

	everyday tasks?				
msis29_v2_q16	Having to cut down the amount of time you spent on work or other daily activities ?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q17	Problems using transport (e.g. car, bus, train, taxi, etc.)?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q18	Taking longer to do things?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q19	Difficulty doing things spontaneously	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely

	(e.g. going out on the spur of the moment) ?				
msis29_v2_q20	Needing to go to the toilet urgently?	Physical Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q21	Feeling unwell?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q22	Problems sleeping?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q24	Worries related to your MS?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q23	Feeling mentally fatigued?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q25	Feeling anxious or tense?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely

msis29_v2_q26	Feeling irritable, impatient, or short-tempered?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q27	Problems concentrating?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q28	Lack of confidence?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
msis29_v2_q29	Feeling depressed?	Psychological Component Single item checkbox	Int	1	1, Not at All 2, A little 3, Moderately 4, Extremely
CompletedDate	NA	Datestamp that the survey was completed	Datetime	15	Timestamp YYYY-MM-DD HH:MM:SS

4.10 Multiple Walking Scale Longitudinal Data: Multiple scores possible for Individuals over time

The MSWS scale is a companion to the MSIS29. Also developed by Hobart et al

Derived from : Hobart JC, Riazi A, Lamping DL, Fitzpatrick R, Thompson AJ. Measuring the impact of MS on walking ability: The 12-Item MS Walking Scale (MSWS-12). *Neurology*. 2003;60:31–36.

MSWS was created by Hobart et al to be a more effective assessment walking alone

Asks for these impressions over the last **two** weeks. Note the different responses in the first 3 questions.

Data can be totalled as a complete score.

FIRST DATA : 12/04/2012

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
v3_msws_decider	Are you able to walk unassisted in any capacity?	Stem question to establish if the patient can walk at all. Historically not asking this first annoys participants. Single item checkbox	Int	1	0, No 1, Yes
v3_msws_blurb1	In the past two weeks, how	Text about the questionnaire			NOT RECORDED

	much has your MS.....				
v3_msws_1	Made it necessary for you to use support when walking indoors (e.g. holding on to furniture, using a stick, etc.)?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not at all 2, Sometimes 3, A Lot
v3_msws_q2	Made it necessary for you to use support when walking outdoors (e.g. holding on to furniture, using a	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not at all 2, Sometimes 3, A Lot

	stick, etc.)?				
v3_msws_q3	Limited your ability to run?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not at all 2, Sometimes 3, A Lot
vs_msws_blurb2	In the past two weeks, how much has your MS.....	Alternative choices from beyond question 3	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q4	Made standing when doing things more difficult?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q5	Limited your ability to climb up and down stairs?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q6	Limited your balance when	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little

	standing or walking?				3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q7	Limited your ability to walk?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q8	Increase the effort needed for you to walk?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q9	Affected how smoothly you walk?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q10	Made you concentrate on your walking?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely

v3_msws_q11	Limited how far you are able to walk?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
v3_msws_q12	Slowed down your walking?	Single item checkbox	Int	1	If v3_msws_decider = 1 1, Not Limited 2, A little 3, Moderately 4, Quite a bit 5, Extremely
CompletedDate	NA	Datestamp that the survey was completed	Date time	15	Timestamp YYYY-MM-DD HH:MM:SS

4.11 Comorbidity Questionnaire : Longitudinal patients can return and enter new comorbidities at any time.

Comorbidity questionnaire, top 50 reported comorbidities in multiple sclerosis

References and Data Source :

1. Marrie RA, Horwitz R, Cutter G, Tyry T, Campagnolo D, Vollmer T. Comorbidity delays diagnosis and increases disability at diagnosis in MS. Neurology. 2009;72:117–124.

2. Marrie RA, Cohen J, Stuve O, et al. A systematic review of the incidence and prevalence of comorbidity in multiple sclerosis: Overview. Mult Scler. 2015;21:263–281.

First Data 12/04/2012

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
v3_no_comorbidity	I have NO other medical conditions, such as diabetes or high blood pressure. I ONLY have multiple sclerosis	Yes/No choice to rule out ANY comorbidity. Defaults to NO Single choice checkbox	Int	1	0, No 1, Yes
v3_comorbid_master	Your other	Multiple choice check box, participants tick as many as			0, Do you have any Cardiac Issues? (ie. heart/blood pressure problems)

	conditions or comorbidities, please tick as many as apply	apply that resolves the detail boxes for that comorbidity.			<p>1, Do you have any Respiratory issues?</p> <p>2, Do you have any Endocrine issues? (ie. diabetes, thyroid issues)</p> <p>3, Do you have any skin related issues?</p> <p>4, Do you have problems related to your bladder/kidneys?</p> <p>5, Do you have problems related to your bowels/gut?</p> <p>6, Do you have problems related to your eyes, ears, nose or throat?</p> <p>7, Other Brain/Nervous system issues - not MS</p> <p>8, Do you have problems related to your bones/skeleton?</p> <p>9, Do you have any issues related to blood?</p> <p>10, I have something else not listed here</p>
v3_comorbid_other	Please state your other condition	Other condition selected that is not listed in the master list	Text	200	If [v3_comorbid_master(10)] = '1'
v3_other_since	Other Condition Since	Date of other condition As YYYY	Int	4	<p>If [v3_comorbid_master(10)] = '1'</p> <p>Bounds 1920-2020</p>
v3_comorbid_cardiac	Cardiac Comorbidities	Mutiple choice check box for cardiac conditions			<p>If [v3_comorbid_master(0)] = '1'</p> <p>0, High cholesterol (hyperlipidemia)</p> <p>1, High blood pressure (hypertension)</p> <p>2, Heart trouble (such as angina, congestive heart failure, or coronary artery disease)</p> <p>3, Disease of arteries in the legs (peripheral vascular disease)</p>
v3_cholesterol_since	High Cholesterol Since:	If patient has indicated High cholesterol (hyperlipidemia) then enter date as YYYY	Int	4	<p>If [v3_comorbid_cardiac(0)] = '1'</p> <p>Bounds 1920-2020</p>

v3_bp_since	High Blood Pressure Since:	If patient has indicated High blood pressure (hypertension) then enter date as YYYY	Int	4	If [v3_comorbid_cardiac(1)] = '1' Bounds 1920-2020
v3_cardiac_ht_since	Heart Trouble Since:	If patient has indicated Heart trouble (such as angina, congestive heart failure, or coronary artery disease) then enter date as YYYY	Int	4	If [v3_comorbid_cardiac(2)] = '1' Bounds 1920-2020
v3_pvd_since	Peripheral Vascular Disease Since:	If patient has indicated Disease of arteries in the legs (peripheral vascular disease) then enter date as YYYY	Int	4	If [v3_comorbid_cardiac(3)] = '1' Bounds 1920-2020
v3_comorbid_respiratory	Respiratory Comorbidities	Multiple choice check box for respiratory conditions	Int	1	If [v3_comorbid_master(1)] = '1' 0, Lung trouble (asthma, emphysema, chronic bronchitis, or COPD) 1, Lung Cancer
v3_asthma_since	Lung Trouble (asthma etc) Since:	If patient has indicated Lung trouble (asthma, emphysema, chronic bronchitis, or COPD) then enter date as YYYY	Int	4	If [v3_comorbid_respiratory(0)] = '1' Bounds 1920-2020
v3_lungcancer_since	Lung Cancer Since:	If patient has Lung Cancer then enter date as YYYY	Int	4	If [v3_comorbid_respiratory(1)] = '1' Bounds 1920-2020
v3_comorbid_endocrine	Endocrine Comorbidities	Multiple choice check box for respiratory conditions	Int	1	If [v3_comorbid_master(2)] = '1' 0, Diabetes mellitus

					1, Thyroid disease (such as Graves' disease, Hashimoto's thyroiditis; not thyroid cancer) 2, Vitamin B 12 deficiency (pernicious anaemia)
v3_diabetes_since	Diabetes Since:	If patient has Diabetes mellitus then enter date as YYYY	Int	4	If [v3_comorbid_endocrine(0)] = '1' Bounds 1920-2020
v3_thyroid_since	Thyroid Disease Since:	If patient has Thyroid disease (such as Graves' disease, Hashimoto's thyroiditis; not thyroid cancer) then enter date as YYYY	Int	4	If [v3_comorbid_endocrine(1)] = '1' Bounds 1920-2020
v3_b12_since	Vitamin B12 Disease Since:	If patient has Vitamin B 12 deficiency (pernicious anaemia then enter date as YYYY	Int	4	[v3_comorbid_endocrine(2)] = '1' Bounds 1920-2020
v3_comorbid_skin	Skin Comorbidities	Multiple choice check box for Skin conditions	Int	1	If [v3_comorbid_master(3)] = '1' 0, Breast Cancer 1, Skin cancer 2, Lupus (systemic lupus erythematosus, SLE)
v3_breastcancer_since	Breast Cancer Since:	If patient has Breast Cancer then enter date as YYYY	Int	4	If [v3_comorbid_skin(0)] = '1' Bounds 1920-2020
v3_skincancer_since	Skin Cancer Since:	If patient has Skin cancer then enter date as YYYY	Int	4	If [v3_comorbid_skin(1)] = '1' Bounds 1920-2020
v3_lupus_since	Lupus Since:	If patient has Lupus (systemic lupus erythematosus, SLE) then enter date as YYYY	Int	4	If [v3_comorbid_skin(2)] = '1' Bounds 1920-2020

v3_comorbid_gu	G/U Diseases	Multiple choice check box Genito Urinary disease	Int	1	If [v3_comorbid_master(4)] = '1' 0, Kidney diseases
v3_kidney_since	Kidney Condition Since:	If patient has Kidney diseases then enter date as YYYY	Int	4	If [v3_comorbid_gu(0)] = '1' Bounds 1920-2020
v3_comorbid_bowel	Bowel/Digestive System Comorbidities	Multiple choice check box Bowel/Digestive System Comorbidities	Int	1	If [v3_comorbid_master(5)] = '1' 0, Cancer of the colon (large bowel) 1, Cancer of the rectum 2, Inflammatory bowel disease(Crohn's disease, ulcerative colitis) 3, Open sore or ulcer in the lining of the stomach, Oesophagus, duodenum (peptic ulcer disease) 4, Liver problems (such as cirrhosis) 5, Irritable bowel syndrome
v3_coloncancer_since	Colon Cancer Since:	If patient has Cancer of the colon (large bowel) then enter date as YYYY	Int	4	If [v3_comorbid_bowel(0)] = '1' Bounds 1920-2020
v3_rectalcancer_since	Rectal Cancer Since:	If patient has Cancer of the rectum then enter date as YYYY	Int	4	If [v3_comorbid_bowel(1)] = '1' Bounds 1920-2020
v3_ibd_since	Inflammatory Bowel Disease Since:	If patient has Inflammatory bowel disease(Crohn's disease, ulcerative colitis) then enter date as YYYY	Int	4	If [v3_comorbid_bowel(2)] = '1' Bounds 1920-2020
v3_ulcer_since	Open Sore or	If patient has Open sore or ulcer in the lining of the	Int	4	If [v3_comorbid_bowel(3)] = '1' Bounds 1920-2020

	Ulcer in the Stomach Lining Since:	stomach, Oesophagus, duodenum (peptic ulcer disease) then enter date as YYYY			
v3_liver_since	Liver Problems Since:	If patient has Liver problems (such as cirrhosis) then enter date as YYYY	Int	4	If [v3_comorbid_bowel(4)] = '1' Bounds 1920-2020
v3_irritable_bd_since	Irritable Bowel Problems Since:	If patient has Irritable bowel syndrome then enter date as YYYY	Int	4	If [v3_comorbid_bowel(5)] = '1' Bounds 1920-2020
v3_comorbid_ent	Ears, eyes Nose and Throat Comorbidity	Multiple choice check box Ears, eyes Nose and Throat Comorbidity	Int	1	If [v3_comorbid_master(6)] = '1' 0, Uveitis (inflammation of the eye) 1, Glaucoma 2, Cataracts
v3_uveitits_since	Uveitits Condition Since:	If patient has Uveitis (inflammation of the eye) then enter date as YYYY	Int	4	If [v3_comorbid_ent(0)] = '1' Bounds 1920-2020
v3_glaucoma_since	Glaucoma Since:	If patient has , Glaucoma then enter date as YYYY	Int	4	If [v3_comorbid_ent(1)] = '1' Bounds 1920-2020
v3_cataracts_since	Cataracts Since:	If patient has , Cataracts then enter date as YYYY	Int	4	[v3_comorbid_ent(2)] = '1' Bounds 1920-2020
v3_comorbid_neuro	Other Neurological, nervous	Multiple choice check box Other Neurological, nervous or Autoimmune conditions	Int	1	If [v3_comorbid_master(7)] = '1' 0, Migraine 1, Epilepsy (seizure disorder)

	or Autoimmune conditions				2, Depression 3, Anxiety 4, Bipolar disorder (manic depression) 5, Schizophrenia
v3_migraine_since	Migraine Since:	If patient has , Migraine then enter date as YYYY	Int	4	If [v3_comorbid_neuro(0)] = '1' Bounds 1920-2020
v3_epilepsy_since	Epilepsy Since:	If patient has , Epilepsy (seizure disorder) then enter date as YYYY	Int	4	If [v3_comorbid_neuro(1)] = '1' Bounds 1920-2020
v3_depression_since	Depression Since:	If patient has , Depression then enter date as YYYY	Int	4	If [v3_comorbid_neuro(2)] = '1' Bounds 1920-2020
v3_anxiety_since	Anxiety Since:	If patient has , Anxiety then enter date as YYYY	Int	4	If [v3_comorbid_neuro(3)] = '1' Bounds 1920-2020
v3_bipolar_since	Bipolar Disorder Since:	If patient has , Bipolar disorder (manic depression) then enter date as YYYY	Int	4	If [v3_comorbid_neuro(4)] = '1' Bounds 1920-2020
v3_schizophrenia_since	Schizophrenia Since:	If patient has , Schizophrenia then enter date as YYYY	Int	4	If [v3_comorbid_neuro(5)] = '1' Bounds 1920-2020
v3_comorbid_skeleton	Skeletal Comorbidity eg Arthritis, skeletal pain	Multiple choice check box Skeletal Comorbidity eg Arthritis, skeletal pain	Int	1	If [v3_comorbid_master(8)] = '1' 0, Rheumatoid arthritis 1, Degenerative arthritis (osteoarthritis) 2, Osteoporosis (bone disease causing thin bones - leading to fractures of the hip, wrist, and spine) 3, Hip replacement(s) 4, Knee replacement(s)

					5, Fibromyalgia 6, Sjögren's syndrome
v3_ra_since	Rheumatoid Arthritis Since:	If patient has, Rheumatoid arthritis then enter date as YYYY	Int	4	[v3_comorbid_skeleton(0)] = '1' Bounds 1920-2020
v3_da_since	Degenerative Arthritis Since:	If patient has, Degenerative arthritis (osteoarthritis) then enter date as YYYY	Int	4	[v3_comorbid_skeleton(1)] = '1' Bounds 1920-2020
v3_osteo_since	Osteoporosis Since:	If patient has Osteoporosis (bone disease causing thin bones -leading to fractures of the hip, wrist, and spine) then enter date as YYYY	Int	4	[v3_comorbid_skeleton(2)] = '1' Bounds 1920-2020
v3_hip_replacement_since	Hip Replacements Since:	If patient has Hip replacement(s) then enter date as YYYY	Int	4	[v3_comorbid_skeleton(3)] = '1' Bounds 1920-2020
v3_kneereplacement_since	Knee Replacements Since:	If patient has Knee replacement(s) then enter date as YYYY	Int	4	[v3_comorbid_skeleton(4)] = '1' Bounds 1920-2020
v3_fibromyalgia_since	Fibromyalgia Since:	If patient has , Fibromyalgia then enter date as YYYY	Int	4	[v3_comorbid_skeleton(5)] = '1' Bounds 1920-2020
v3_sjogrens_syndrome	Sjögren's Since:	If patient has Sjögren's syndrome then enter date as YYYY	Int	4	[v3_comorbid_skeleton(6)] = '1' Bounds 1920-2020

v3_comorbid_blood	Blood diseases	Multiple choice check box Blood diseases	Int	1	If [v3_comorbid_master(9)] = '1' 0, Anaemia or other blood disease
v3_anaemia_since	Anaemia Since:	If patient has Anaemia or other blood disease then enter date as YYYY	Int	4	[v3_comorbid_blood(0)] = '1' Bounds 1920-2020
CompletedDate	NA	Datestamp that the survey was completed	DateTime	15	Timestamp YYYY-MM-DD HH:MM:SS

4.12 Current Patient Symptoms, Longitudinal

Records date experienced and severity of patients Symptoms
Source PwMS, Clinical Advisory Group

The symptoms questionnaire was vastly revised for v3 of the portal. Version 1-2 only captured if a symptom was present or not (same symptoms as below) and a timestamp that this was this data was imported to version 3. Some detail may therefore be missing in symptom data prior to 01/08/2018

Symptoms First Data : 10/10/2011

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
v3_symptoms_present	I have symptoms directly related to my Multiple Sclerosis	Does the patient have symptoms related to their MS? Yes to enter			0, No 1, Yes
v3_symptoms_list	Symptoms	Multiple choice check box so as many symptoms are being experienced can be entered	Int	2	If [v3_symptoms_present] = '1' 0, Optic Neuritis - Sudden loss of vision 1, Double Vision - 2 images of a single object 2, Impairment of motor control - loss of function in movement 3, Sensory Loss - lack of sensation 4, Parasthesia (pins and needles) 5, Muscle Pain 6, Bladder Problems - incontinence or urgency

					<p>7, Bowel Problems - incontinence or constipation 8, Sexual Dysfunction - sexual problems 9, Altered Sensation - Change in feeling of touch 10, Weakness - lacking strength in affected area 11, Spasticity - muscle tightness 12, Difficulty Swallowing - problems swallowing food or drink 13, Difficulty speaking 14, Trigeminal Neuralgia - facial pain 15, Tremors - shaking on fine movement 16, Dysarthria - slurred speech 17, Nystagmus - jerky/shaky eye movement 18, Fatigue - tiredness 19, Depression 20, Pain - generalised pain 21, Cognitive Difficulties - Memory problems 22, Brief Repetitive Symptoms - same symptoms occurring over and over 23, Gait - walking difficulties 24, Ataxia - lack of voluntary coordination of muscle movements</p>
v3_symptoms_on_since_0	Optic Neuritis Since:	If Optic Neuritis - Sudden loss of vision, then enter date as YYYY	Int	4	If [v3_symptoms_list(0)] = '1'
v3_symptoms_on_severity_0	Optic Neuritis Severity	Enter severity of Optic Neuritis Single choice checkbox	Int	1	<p>0, Mild 1, Moderate 2, Severe</p>

v3_symptoms_dv _since_1	Double Vision Since:	If Double Vision then enter date as YYYY	Int	4	If [v3_symptoms_list(1)] = '1'
v3_symptoms_dv _severity_1	Double Vision Severity	Enter severity of Double Vision Single choice checkbox	Int	1	[If v3_symptoms_list(1)] = '1' 0, Mild 1, Moderate 2, Severe
vs_symptoms_mc _since_2	Impairm ent in motor control Since:	If motor control impairment - then enter date as YYYY	Int	4	If [v3_symptoms_list(2)] = '1'
v3_symptoms_m c_severity_2	Impairm ent in motor control severity	Enter severity of motor control impairment Single choice checkbox	Int	1	If [v3_symptoms_list(2)] = '1' 0, Mild 1, Moderate 2, Severe
vs_symptoms_se nsory_since_3	Sensory Loss Since:	If Sensory loss, then enter date as YYYY	Int	4	If [v3_symptoms_list(3)] = '1'
vs_symptoms_se nsory_severity_3	Sensory Loss Severity	Enter severity of Sensory loss Single choice checkbox	Int	1	If [v3_symptoms_list(3)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_pi ns_needles_since _4	pins and needles since:	If pins and needles - then enter date as YYYY	Int	4	If [v3_symptoms_list(4)] = '1'
v3_symptoms_pi ns_needles_sever ity_4	pins and needles severity	Enter severity of pins and needles Single choice checkbox	Int	1	If [v3_symptoms_list(4)] = '1' 0, Mild

					1, Moderate 2, Severe
v3_symptoms_muscle_pain_since_5	Muscle Pain Pain since:	If muscle pain, then enter date as YYYY	Int	4	If [v3_symptoms_list(5)] = '1'
v3_symptoms_muscle_pain_severity_5	Muscle Pain Pain Severity	Enter severity of muscle pain Single choice checkbox	Int	1	If [v3_symptoms_list(5)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_bladder_problems_since_6	Bladder Problems Bladder Problems Since:	If Bladder Symptoms then enter date as YYYY	Int	4	If [v3_symptoms_list(6)] = '1'
v3_symptoms_bladder_problems_severity_6	Bladder Problems Bladder Problems Severity :	Enter severity of Bladder Symptoms Single choice checkbox	Int	1	If [v3_symptoms_list(6)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_bowel_problems_since_7	Bowel Problems Bowel Problems Since:	If Bowel Symptoms then enter date as YYYY	Int	4	If [v3_symptoms_list(7)] = '1'
v3_symptoms_bowel_problems_severity_7	Bowel Problems Bowel Problems Severity :	Enter severity of Bowel Symptoms Single choice checkbox	Int	1	If [v3_symptoms_list(7)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_sexual_problems_since_8	Sexual problems Sexual problems Since:	If sexual symptoms then enter date as YYYY	Int	4	If [v3_symptoms_list(8)] = '1'
v3_symptoms_sexual_problems_severity_8	Sexual problems Sexual problems Severity	Enter severity of sexual symptoms Single choice checkbox	Int	1	[v3_symptoms_list(8)] = '1' 0, Mild

					1, Moderate 2, Severe
v3_symptoms_altered_sensation_since_9	Altered Sensation Since:	If altered sensation then enter date as YYYY	Int	4	If [v3_symptoms_list(9)] = '1'
v3_symptoms_altered_sensation_severity_9	Altered Sensation Severity	Enter severity of altered sensation Single choice checkbox	Int	1	If [v3_symptoms_list(9)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_weakness_since_10	Weakness Since:	If weakness symptoms then enter date as YYYY	Int	4	If [v3_symptoms_list(10)] = '1'
v3_symptoms_weakness_severity_10	Weakness Severity	Enter severity of weakness Single choice checkbox	Int	1	If [v3_symptoms_list(10)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_spasticity_since_11	Spasticity Since:	If Spasticity symptoms, then enter date as YYYY	Int	4	If [v3_symptoms_list(11)] = '1'
v3_symptoms_spasticity_severity_11	Spasticity Severity	Enter severity of If Spasticity symptoms Single choice checkbox	Int	1	If [v3_symptoms_list(11)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_swallowing_since_12	Difficulty Swallowing Since:	If Swallowing symptoms, then enter date as YYYY	Int	4	If [v3_symptoms_list(12)] = '1'
v3_symptoms_swallowing_severity_12	Difficulty Swallowing Severity	Enter severity of Swallowing symptoms Single choice checkbox	Int	1	If [v3_symptoms_list(12)] = '1' 0, Mild 1, Moderate 2, Severe

v3_symptoms_speaking_since_13	Difficulty speaking Since:	If speaking symptoms, then enter date as YYYY	Int	4	If [v3_symptoms_list(13)] = '1'
v3_symptoms_speaking_severity_13	Difficulty speaking Severity	Enter severity of speaking symptoms Single choice checkbox	Int	1	If [v3_symptoms_list(13)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_tna_since_14	Trigeminal Neuralgia Since:	If Trigeminal Neuralgia symptoms, then enter date as YYYY	Int	4	If [v3_symptoms_list(14)] = '1'
v3_symptoms_tna_severity_14	Trigeminal Neuralgia Severity	Enter severity of Trigeminal Neuralgia Single choice checkbox	Int	1	If [v3_symptoms_list(14)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_tremors_since_15	Tremors Since:	If tremors then enter date as YYYY	Int	4	If [v3_symptoms_list(15)] = '1'
v3_symptoms_tremors_severity_15	Tremors Severity	Enter severity of tremors Single choice checkbox	Int	1	If [v3_symptoms_list(15)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_dysarthria_since_16	Dysarthria Since:	If dysarthria, then enter date as YYYY	Int	4	If [v3_symptoms_list(16)] = '1'
v3_symptoms_dysarthria_severity_16	Dysarthria Severity	Enter severity of dysarthria Single choice checkbox	Int	1	[v3_symptoms_list(16)] = '1' 0, Mild 1, Moderate 2, Severe

v3_symptoms_nystagmus_since_17	Nystagmus Since:	If nystagmus, then enter date as YYYY	Int	4	If [v3_symptoms_list(17)] = '1'
v3_symptoms_nystagmus_severity_17	Nystagmus Severity	Enter severity of nystagmus Single choice checkbox	Int	1	If [v3_symptoms_list(17)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_fatigue_since_18	Fatigue Since:	If fatigue, then enter date as YYYY	Int	4	If [v3_symptoms_list(18)] = '1'
v3_symptoms_fatigue_severity_18	Fatigue Severity	Enter severity of fatigue Single choice checkbox	Int	1	If [v3_symptoms_list(18)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_depression_since_19	Depression Since:	If depression, then enter date as YYYY	Int	4	If [v3_symptoms_list(19)] = '1'
v3_symptoms_depression_severity_19	Depression Severity	Enter severity of depression Single choice checkbox	Int	1	If [v3_symptoms_list(19)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_pain_since_20	Pain Since:	If pain - Sudden loss of vision, then enter date as YYYY	Int	4	If [v3_symptoms_list(20)] = '1'
v3_symptoms_pain_severity_20	Pain Severity	Enter severity of pain Single choice checkbox	Int	1	If [v3_symptoms_list(20)] = '1' 0, Mild 1, Moderate 2, Severe

v3_symptoms_cognitive_difficulty_since_21	Cognitive Difficulties Since:	If cognitive issues, then enter date as YYYY	Int	4	If [v3_symptoms_list(21)] = '1'
v3_symptoms_cognitive_difficulty_severity_21	Cognitive Difficulties Severity	Enter severity of cognitive issues Single choice checkbox	Int	1	[v3_symptoms_list(21)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_brief_symptoms_since_22	Brief Repetitive Symptoms Since:	Brief repetitive symptoms then enter date as YYYY	Int	4	If [v3_symptoms_list(22)] = '1'
v3_symptoms_brief_symptoms_severity_22	Brief Repetitive Symptoms Severity	Enter severity of Brief repetitive symptoms Single choice checkbox	Int	1	If [v3_symptoms_list(22)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_gait_issues_since_23	Gait issues Since:	If gait issues, then enter date as YYYY	Int	4	If [v3_symptoms_list(23)] = '1'
v3_symptoms_gait_issues_severity_23	Gait issues Severity	Enter severity of gait Single choice checkbox	Int	1	If [v3_symptoms_list(23)] = '1' 0, Mild 1, Moderate 2, Severe
v3_symptoms_ataxia_since_24	Ataxia issues Since:	If ataxia then enter date as YYYY	Int	4	If [v3_symptoms_list(24)] = '1'

v3_symptoms_ataxia_severity_24	Ataxia issues Severity	Enter severity of ataxia Single choice checkbox	Int	1	If [v3_symptoms_list(24)] = '1' 0, Mild 1, Moderate 2, Severe
CompletedDate	NA	Datestamp that the survey was completed	Date time	15	Timestamp YYYY-MM-DD HH:MM:SS

4.13 Patient Relapses : Longitudinal multiple rows per patient.

Reports of relapses in patients, patient must select v3_rr_mstype_now = 1 to see this table
 Data Source : pwMS, Clinical Advisory Group

First Data 01/08/2018

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
v3_relapses_any	Have you had ANY relapses in the last 6 months?	Has the patient had any relapses in the last 6 months Single choice check box	Int	1	0, No 1, Yes
v3_relapses_number	How many relapses have you had in the last 6 months?	Number of relapses in the last six months Text field	Int	2	If [v3_relapses_any] = '1' Bounds 0 - 20
v3_relapse_month	When did the most recent one happen? Please	What month did the most recent one happen in? Single choice check box	Int	2	If [v3_relapses_any] = '1' 0, Don't Know 1, Jan 2, Feb 3, Mar 4, Apr

	enter a month				5, May 6, June 7, July 8, August 9, Sept 10, Oct 11, Nov 12, Dec
v3_relapses_severity	How bad was your most disabling relapse in this 6 month period?	Severity of relapse, If number entered is more than one. Single choice check box	Int	1	If ([v3_relapses_number] >= 1) 0, Mild 1, Moderate 2, Severe
v3_relapse_hospitalisation	Were you hospitalised for this relapse?	Was hospitalisation required for this most severe relapse	Int	1	If [v3_relapses_any] = '1' 0, No 1, Yes
CompletedDate	NA	Datestamp that the survey was completed	Datetime	15	Timestamp YYYY-MM-DD HH:MM:SS

4.14 WebEDSS : Longitudinal multiple results per patient.

The webEDSS is used with permission from Leddy et al Leddy S, Hadavi S, McCarren A, Giovannoni G, Dobson R. Validating a novel web-based method to capture disease progression outcomes in multiple sclerosis. Journal of Neurology. 2013;260:2505–2510.

Data is sourced from an API from a javascript implementation of the instrument run on a third party server. No patient data is transmitted to this server just a GUID. The returned data from the server is matched to the GUID and the score and datestamp stored on the MS Register platform,

NOTE : Participants can enter multiple scores in seconds of each other by pressing 'back' on the instrument and making slight changes to their answers. The Registers internal policy is to use the first result on a day as the 'correct' one.

First Data : 22/11/2016

Variable	Field Label	Description	Type	Length	Values
UserId	UserId	Unique patient identifier	Int	6	Common userid to allow linkage across multiple extracted data
webEDSS		Patients EDSS Score	Float	3	0 .0– 10.0
CompletedDate	NA	Datestamp that the survey was completed	Datetime	15	Timestamp YYYY-MM-DD HH:MM:SS