SCOTTISH MS REGISTER
INCIDENCE FORM CORE DATASET
DEFINITIONS AND VALUES

Version 12 updated January 2019

Inclusion Criteria:
A form should be completed once a patient has a **confirmed diagnosis of Multiple Sclerosis**.
A confirmed diagnosis is classed as: *A clinically definite diagnosis of Multiple Sclerosis based on the McDonald criteria.*

Patients should only be included in the MS Register if their **confirmed diagnosis occurred after 01.01.2010**.

Exclusion Criteria:
Patients diagnosed pre 2010.
Patients who are noted as having Clinically Isolated Syndromes or 'possibly MS'.

DATA ITEMS	DEFINITIONS	VALUES *(Information required on proforma)*
1. General Information		
1.1 CHI Number	**Mandatory identifier.** Community Health Index (CHI) Number giving the patient a unique, national, reference number (10 characters).	Enter 10 characters *Consisting of the 6-digit date of birth (DDMMYY), two digits, a 9th digit which is always even for females and odd for males and an arithmetical check digit.* **No CHI number** If the patient has not been assigned a CHI then enter the date of birth (DDMMYY) and 0000 as the CHI, *e.g. if the patient's DOB is 12.08.1954 you would enter 1208540000*. Enter characters in table view first.
1.2 Has the patient declined MS nurse support?	Record whether the patient has declined the support of the MS nursing service.	Please select code from the drop down options.
2. Data Collection		
2.1 Hospital/ Centre	Record the name of the **hospital/ centre** where the MS incidence form was **completed** and **submitted** to the MS Register team **from** using the codes provided. The most commonly coded hospitals in the SMSR since 2010 are listed on the drop down options.	Please select code from the drop down options.
2.2 Completed by	Record the name of the **person** who has **completed** the form and submitted it to the MS Register team.	Free text – enter person's name
3. Personal details		
3.1 Surname	"The **surname** of a person represents that part of the name of a person which indicates the family group of which the person is part." (From the Core Patient Profile Information in Scottish Hospitals (COPPISH) SMR Data Manual Version 1.1; issued November 1995 p2-5)	Free text - enter surname.

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3.2 Forename	"The **first forename** of a person represents that part of the name of a person which, after the surname, is the principal identifier of a person." (From the COPPISH SMR Data Manual version 1.1; issued November 1995 p2-6) When recording names be aware of different conventions for order for parts of the name used in different cultures"	Free text - enter forename.
3.3 Patient Postcode	Record complete **postcode of patient's normal permanent place of residence**, e.g. home, nursing home, NHS continuing care etc. at time of diagnosis of MS. If the patient is already in hospital for temporary short term care their normal permanent place of residence postcode should be used and not that of the hospital where they are temporarily an inpatient.	Patients with UK postcode – enter full postcode (up to 7 digits).
3.4 Gender	Record **gender** from the drop down options. A statement by the individual about the gender they currently identify themselves to be (i.e. self-assigned).	Please select code from the drop down options.
3.5 Ethnicity	Record the patient's **ethnic origin** - a statement made by the service user re their current ethnic group. From the COPPISH data manual. All Boards have a requirement to collect ethnicity data routinely. If ethnicity is not clearly documented in the patient's notes, please record 'not known'.	Please select code from the drop down options.
3.6 GP name	**Name of the GP** the patient is registered with at the time of the diagnosis of MS.	Free text – enter name of GP
3.7 GP address	**GP address** is defined as – GP/ practice address patient registered with at time of MS diagnosis.	Free text – enter address of GP practice.
3.8 Country of birth	Record the **country of birth**, i.e. where the patient was born.	Please select code from the drop down options.
3.9 City/ town of birth	Record the **city/ town of birth**, i.e. where the patient was born.	Free text – enter name of city/ town.
3.10 Employment status at time of diagnosis?	Record the patient's **employment status** at time of diagnosis of MS.	Please select code from the drop down options.
3.11 If sick/ disabled, is this as a result of MS?	If the patient has noted that they are **registered sick or disabled**, please note if this is **as a result of their diagnosis of MS/ MS symptoms**.	Please select code from the drop down options.
3.12 If employed/ self employed: regular/ average number of hours/ week.	Record the **regular/ average number hours per week** that the patient is in paid employment (to nearest whole hour).	Enter characters to reflect number of hours. If 'Not disclosed' select code 97 If 'Not known' select code 99
3.13 Domestic/ marital status at time of diagnosis?	Record the patient's **domestic/ marital status** at time of diagnosis of MS.	Please select code from the drop down options.
3.14 Does any 1st degree family member have a diagnosis of MS?	Record if the patient has a **known first degree family member** who has a diagnosis of MS. A first degree relative can be defined as a parent, sibling or child. If the patient does not know their 1st degree family please record 'not known'.	Please select code from the drop down options.

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4. Investigations		
4.1 Was a brain MRI carried out?	Record if the patient had a **brain MRI** carried out leading to the current confirmed diagnosis of MS.	Please select code from the drop down options.
4.2 Was a spinal cord MRI carried out?	Record if the patient had a **spinal cord MRI** carried out leading to the current confirmed diagnosis of MS.	Please select code from the drop down options.
4.3 Was a lumbar puncture carried out?	Record if the patient had a **lumber puncture** carried out leading to the current confirmed diagnosis of MS.	Please select code from the drop down options.
4.4 Were oligoclonal bands present?	Record if the patient presented with **oligoclonal bands** leading to the current confirmed diagnosis of MS.	Please select code from the drop down options.
5. Referral to CONFIRMED Diagnosis		
5.1 Date of 1st onset of symptoms.	Record the **date the patient first recalls experiencing symptoms** consistent with their diagnosis of MS. It is understood that this date can often be vague – please follow instructions in next column if you are only able to provide a partial date.	Enter date *(DD/MM/YYYY)* If only a partial date is available complete the date field as follows placing an 'X' in the box if unknown. Year only: XX/XX/2005 Month and year: XX/03/2005
5.2 Date of initial referral to Neurology	Record the date of initial referral from GP (or other) to Neurology	Enter date *(DD/MM/YYYY)* If only a partial date is available complete the date field as follows placing an 'X' in the box if unknown. Year only: XX/XX/2005 Month and year: XX/03/2005
5.3 Date seen in Neurology	Record the date the patient was seen in general Neurology following initial referral. If the patient was sent to an MS Specialist Neurology following initial referral enter XX/XX/XXXX and enter date in question 5.4	Enter date *(DD/MM/YYYY)* If only a partial date is available complete the date field as follows placing an 'X' in the box if unknown. Year only: XX/XX/2005 Month and year: XX/03/2005
5.4 Date patient was referred to specialist MS Neurologist	Record the date the patient was referred to the MS neurologist for a confirmed diagnosis. This may be from general neurology/ ward/ GP.	Enter date *(DD/MM/YYYY)* If only a partial date is available complete the date field as follows placing an 'X' in the box if unknown. Year only: XX/XX/2005 Month and year: XX/03/2005
5.5 Who confirmed the diagnosis of MS?	Record the **type of neurologist (or other clinician)** who confirmed the patient's diagnosis of MS. If 'other' please specify using free text in capital letters.	Please select code from the drop down options.
5.6 Diagnosing Hospital	Record the name of the **hospital/ centre** where the patient received their diagnosis of MS.	Please select code from the drop down options.
5.7 Date of confirmed diagnosis	Record the **date** the patient received a **confirmed diagnosis** of MS. This may be recorded specifically by the diagnosing clinician or it may be the clinic date when the patient was seen and diagnosis confirmed.	Enter date *(DD/MM/YYYY)*
5.8 Type of MS	Record the **type of MS** noted when the patient was given a confirmed diagnosis.	Please select code from the drop down options.

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5.9 Was the patient offered DMT's ?	Record if the patient was offered disease modifying treatment.	Please select code from the drop down options.
6. First MS contacts – Following Confirmed Diagnosis		
6.1 Date of referral to the MS nurse.	Record the **date the patient was referred to the MS nurse** following confirmed diagnosis.	Enter date (DD/MM/YYYY)
6.2 Date the referral was received by the MS nurse.	Record the **date the referral was received by the MS nurse** following confirmed diagnosis.	Enter date (DD/MM/YYYY)
6.3 Date of first contact with MS nurse.	Record the date the patient was **first contacted and/ or seen by the MS nurse** following confirmed diagnosis.	Enter date (DD/MM/YYYY)
6.4 Type of contact with MS nurse.	Record the type of **contact made with the MS nurse**.	Please select code from the drop down options.