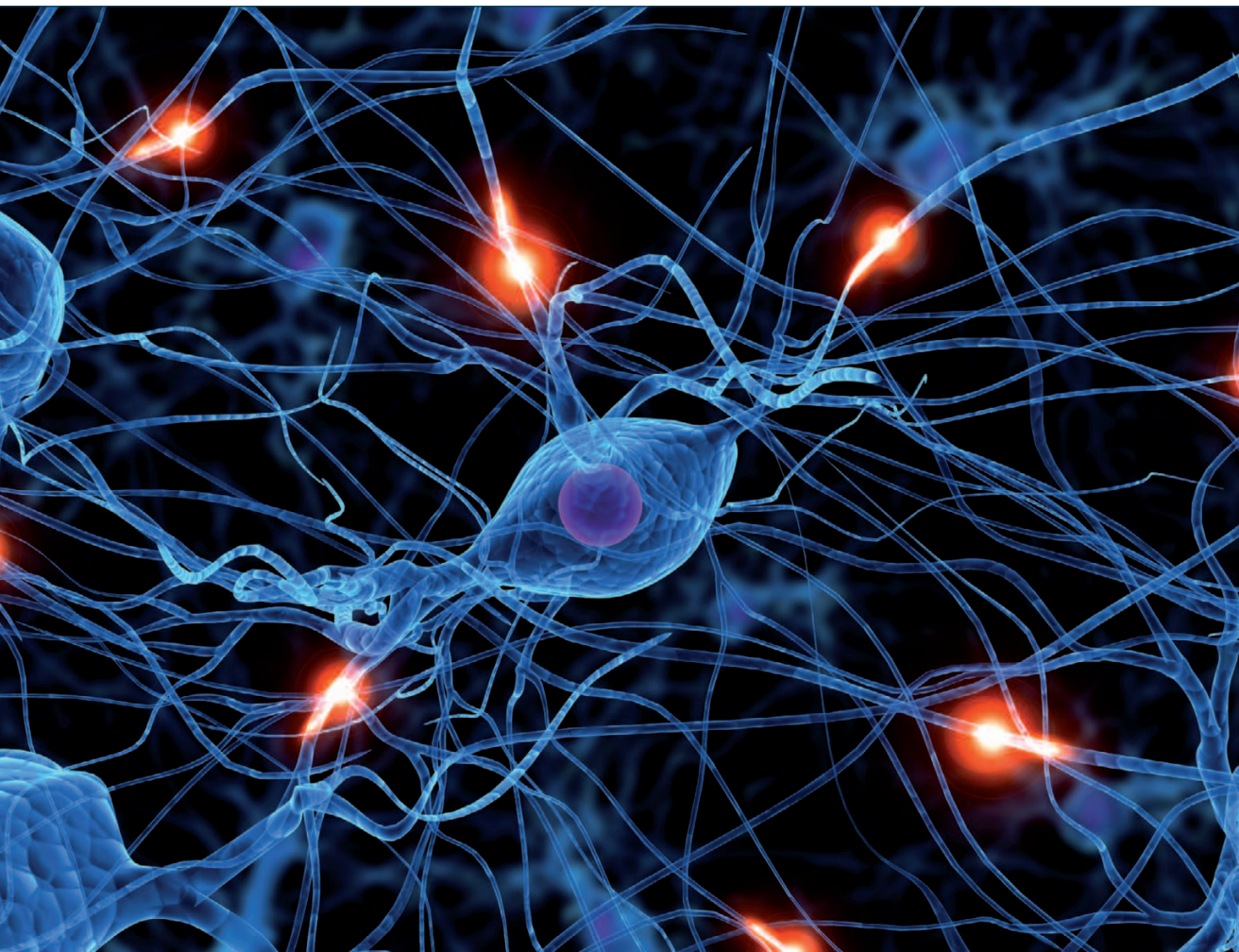




# Scottish Multiple Sclerosis Register First National Report 2011

Data relating to 01.01.10 till 21.12.2010



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# Introduction

In 2009, funding was provided by the Scottish Government to set up the [Scottish Multiple Sclerosis Registry](#). We started collecting information in 2010 with the help of the MS nurse specialists and neurologists around Scotland and we are now reporting on the results of our first year of activity.

The [MS Society](#) has been involved in the Scottish MS Register since its inception. The MS Society has worked with [ISD](#) and the Steering Group to develop a register that has people with MS as its focus and this collaboration has proved effective. The steering group directs the activities of the Scottish MS Register and it comprises Consultant Neurologists from each health board, a patient representative, and representatives from the Scottish MS nurse group, Information Services Division, a Physiotherapist, a Consultant Epidemiologist as well as the Director of the MS Society Scotland. There is also a parallel patient representative group made up of people with MS and their carers. Both of these groups work collaboratively to guide the direction of the Scottish MS Register.

The Scottish MS Register is working with the [MS Society's UK Register project](#). This project has built a working prototype register system that will be collecting information from three information sources: firstly, from people with MS via a [secure internet portal](#), secondly, from clinical systems in

5 NHS MS teams from around the UK, (Edinburgh being the Scottish participant), and thirdly, for the 5 NHS MS teams participating in the project, their data will be combined with routinely collected NHS patient information.

Both registers will help us to develop an information system that will increase understanding and knowledge about MS at an individual and societal level, allowing regional and national authorities to make informed and tailored decisions about MS service provision.

The Scottish MS Register is a forum for interaction between people with MS and their carers, clinicians and the voluntary sector. There is a great opportunity for Scotland to continue to develop this unique register of those newly diagnosed with MS.

In spite of inevitable problems in getting data from across Scotland, the data from the first year of the Scottish MS Register provide a picture of the potential of the register in its ability to provide a benchmark against which clinicians can raise standards and drive improvements in MS management across NHS Scotland.

**Belinda Weller**  
Chair of Scottish MS Register

# Acknowledgements

The steering group of the Scottish MS Register would like to thank the staff in all of the neurological and neurological rehabilitation units in Scotland for their help with data collecting and checking.

The clinical leads for each of the hospitals are listed below:

NHS Health Board	Hospital	Lead Consultant
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Paul Mattison
Borders	Borders District General	David Simpson
Dumfries & Galloway	Dumfries General Royal Infirmary	Locum
Fife	Cameron Hospital	Lance Sloan
	Victoria Hospital Kirkcaldy	Uwe Spelmeyer
Forth	Forth Valley Royal Hospital	Christian Neumann
Grampian	Aberdeen Royal Infirmary	Margaret Ann MacLeod
Greater Glasgow & Clyde	Institute of Neurological Science	Colin O'Leary/ James Overell
Highlands	Raigmore Hospital	Bethany Jones
Lothian	Western General Hospital	Belinda Weller (Chair)
Tayside	Ninewells Hospital	Johnathan O'Riordan
	Perth Royal Infirmary	Johnathan O'Riordan

We are extremely grateful for the help and support they have given to help us continually improve the information collected.

# What is Multiple Sclerosis?

Multiple sclerosis is the result of damage to myelin—a protective sheath surrounding nerve fibres of the central nervous system. The central nervous system comprises the brain and spinal cord. Together with the nerves connecting to the rest of the body, they form the body's communication network.

In the earlier stages of MS, the central nervous system can often repair areas of damaged myelin or reroute messages via different pathways of neurons thereby avoiding the damaged areas. This explains why episodes of symptoms (relapses) can be followed by weeks, months or even years when symptoms improve or disappear (remission). However, if

the area of damage becomes too large, communication with that specific part of the central nervous system may become permanently blocked.

For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

It is often said that MS is the “Scottish disease” so it is important to know how many people in Scotland are diagnosed with the condition each year and also both where and how they are diagnosed. This information will be useful to help in planning the sort of services that people with MS need.

## Aim of Scottish MS Register

The aim of the Scottish MS register is to make services for people with MS in Scotland more patient-centred, safe and effective in line with the three quality ambitions of the NHS Healthcare Quality Strategy. This is achieved by establishing the incidence of MS in Scotland, to interpreting the implications of its demography and so enabling service evaluation and quality improvement.

Information collected is:

- Demographic information
- Family information (MS)
- First symptoms
- Referrals
- MS nurse contact
- Investigation types used
- Type of MS at time of diagnosis

Two pilot studies were carried out in September and November 2009 resulting in the following exclusions.

Information excluded:

- Co-morbidity information is not systematically recorded in enough detail to be useful to collect.
- Investigation results are time consuming and the amount of detail submitted varied between hospitals.

- Outcome measure information is not routinely collected in any of the hospitals.
- Vitamin D information is not routinely collected by any of the centres. In the past Dundee had collected vitamin D blood levels but had stopped due to the lack of guidelines on vitamin prescribing and the cost of blood analysis.

The information that has been excluded, further discussion is required at a national level to establish:

- clear definition of the information being collected;
- what point in time of the patient's journey is the information to be collected;
- the amount of detail it is effective to ask busy clinicians to collect and send to the register.

The Steering Group has suggested that it may be more effective if additional information collected about specific topics relating to MS be carried out by MS teams as a short term piece of work with a designated consultant to lead.

# Methodology

Data on all known patients registered by a Consultant Neurologist with a new diagnosis of MS from 1<sup>st</sup> January 2010 in Scotland were collected using a standard proforma, which incorporated the patient journey from referral to diagnosis, including referral to a MS nurse specialist. Analysis of the data was undertaken, including outline data checks to ensure data quality and validity.

This report includes data on all people registered in Scotland by a Consultant Neurologist with a new diagnosis of MS since 01.01.2010 to 31.12.2010.

Means and medians are used in the report as measures of central tendency within a data range.

A mean is the mathematical average (i.e. sum of the values divided by the number of items in the data range). This is an exact measure of central tendency, but can be unsuitable in data ranges where there are outliers, which may skew the results. The median on the other hand is simply the point at which, if values in the data range were to be sorted from high to low (or vice versa), the middle point would lie. While this avoids the distortion problems encountered using the mean, it is not an exact measure and may not reflect clustered values either side of the middle point in the data range. To overcome these issues, both measures are sometimes quoted within this report.

## Progress to date

The steering group directs the activities of the Scottish MS Register. In 2010 the register has focused on:

- Maintaining engagement with all relevant stakeholders as it is vital for the information collected to be meaningful to all parties to enable them to improve the service to people with MS and their carers.
- Improving current processes to enable the register to record all people with a new diagnosis of MS from 01.01. 2010.
- Reducing duplication of information collection. As such, the register has investigated the current data sets that may be useful to link with in the future to reduce information completed by the clinicians. This linkage will also be utilised to improve quality of data and to improve data capture for example, outpatient attendance, inpatient attendance, and prescribing information.
- Full review of data set and redesign of data definition by 30.09.2011.
- Contribution to the formulation of a national strategy and reporting on compliance with national clinical standards.
- Collaborative projects/data linkage/academic publications.

## Review of Information

Analysis of the data suggested under reporting by general neurologists in Fife, Lanarkshire and Ayrshire.

Investigation of the patient pathway in Fife has identified that both acute and rehabilitation services are required to participate in informing the register of a person who is newly diagnosed with MS. Fife has predicted 40 to 48 people with a new diagnosis of MS per year. Fife now has 4 General Neurologists, one of which has an interest in MS.

He has agreed to take forward informing the register of people with a new diagnosis of MS. Fife MS Rehabilitation Services in Primary Care has agreed to inform the register of any referrals from the acute service.

Lanarkshire has a MS nurse specialist in post since August 2011 who has agreed to inform the Scottish MS register of any referrals to Lanarkshire MS services. SW Scotland Neurological Services are under review—the Scottish MS register is awaiting

confirmation of the name of the General Neurologist who will be responsible for Lanarkshire.

Investigation of the patient pathway in Ayrshire & Arran has identified that both acute and rehabilitation services are required to participate in informing the register of a person who is newly diagnosed with MS. Douglas Grant Rehabilitation centre estimate that their MS team have received 40 to 50 referrals of people with a new diagnosis of MS in 2010. The register has only received 12. The Scottish MS register is exploring the possibility of capturing missing information for 2010 by utilising information available from the Douglas Grant

Rehabilitation Team for missing information made by General Neurologists from GGHB who make new diagnosis for people with MS in Ayrshire.

The MS team from Greater Glasgow Health Board & Clyde (GGHB&C) has highlighted issues surrounding compliance of General Neurologists in GGHB & C to complete the form, appropriateness of clinician time and lack of administrative support. There is the possibility of employment of another MS nurse specialist and small additional administrative support, who may in the future help support and coordinate register form completion for GGHB & C.

## Future Work

- As the register will have identified people who are newly diagnosed with MS, the register data will be linked with routinely collected hospital information on out patient attendances and inpatient admissions. Both sets of information will be compared against each other in an effort to improve data quality.
- Review and simplification of the data collected by the register. Full review of the data set and redesign of data definition by 30.09.11.
- Use of redesigned dataset and related documentation to commence 01.10.2011.
- Contribution to the formulation of a national strategy.
- Reporting on compliance with national clinical standards.
- Collaborative projects/data linkage/ academic publications.

Additional Information is available on the [Scottish MS Register website](#) for the following information:

- Aims and methods of audit
- Data definitions
- Audit documentation
- Patient leaflets and posters

## Key points

The first year of information shows:

- A total of 344 people were entered onto the Scottish MS Incidence Register in 2010 (1<sup>st</sup> Jan–31<sup>st</sup> Dec). This number is lower than expected when compared to clinicians' pre-register estimates
- 99% of people had a brain MRI, 21% prior to referral to neurology, with a further 48% within six weeks of seeing a General Neurologist, 84% by 12 weeks.
- Following diagnosis, people with MS are offered a referral to a specialist MS nurse. Clinical Standards—October 2009, Neurological Health Services, Standard 15: Diagnosis of multiple sclerosis, 15.2 states that:

'Contact with an MS clinical nurse specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of diagnosis.' 8% of people were supported by MS nurse specialist prior to be given their diagnosis. 51% of people newly diagnosed with MS had contact with MS nurse specialist within two weeks of diagnosis, and 79% of all people being contacted within 6 weeks of diagnosis.

# Results

A total of 344 people were entered onto the Scottish MS Incidence Register in 2010 (1<sup>st</sup> Jan–31<sup>st</sup> Dec). This number is lower than expected when compared to clinicians' pre-register estimates (Table 1). Throughout the remainder of this report the term 'people diagnosed' refers to people who were entered onto the Register in 2010.

**Table 1** How many people were diagnosed with MS in 2010 and how does this compare with pre-register estimates?

Hospital/NHS Board	Actual	Estimated
Aberdeen Royal Infirmary, Grampian	53	48–72
Borders District General, Borders	6	12–24
Cameron Hospital, Fife	0	25–30
Douglas Grant Rehabilitation Centre, Ayrshire and Arran	8	1–2
Dumfries General Royal Infirmary, Dumfries and Galloway	10	12–24
Forth Valley Royal Hospital, Forth	17	12–24
Gilbert Bain Hospital, Shetland	0	0
Institute of Neurological Science, GGHB&C	146	180–240
Ninewells Hospital & Perth Royal Infirmary, Tayside	42	48
Raigmore Hospital, Highlands	13	12–24
Victoria Hospital, Fife	0	12–24
Western General Hospital, Lothian	49	48–72
<b>Total</b>	<b>344</b>	<b>400–500</b>

While strenuous efforts were made to maximise data capture for all variables, it should be noted that some data are incomplete. This being the case, results presented within this report should be used for indicative purposes only and should be interpreted with care.

Tables 2 to 6 present a summary of the demographic information collected for all people who were diagnosed with MS in Scotland in 2010. Please note the high number of cases for which information was not disclosed or was not known.

**Table 2** Country of Birth

Country of Birth	Number of people diagnosed	% of people diagnosed
Scotland	161	46.8%
Other UK	14	4.1%
Other	10	02.9%
Unknown/not disclosed	159	46.2%
<b>Total</b>	<b>344</b>	<b>100.0%</b>



**Table 3** Ethnicity

Ethnicity	Number of people diagnosed	% of people diagnosed
White Scottish	243	70.7%
White other UK	18	5.2%
Any other white	9	2.6%
Other	6	1.7%
Unknown/not disclosed	68	19.8%
<b>Total</b>	<b>344</b>	<b>100.0%</b>

**Table 4** Domestic Status

Domestic Status	Number of people diagnosed	% of people diagnosed
Living alone	44	12.8%
Living with spouse/partner	160	46.5%
Living with family	97	28.2%
Other	3	0.9%
Unknown/not disclosed	40	11.6%
<b>Total</b>	<b>344</b>	<b>100.0%</b>

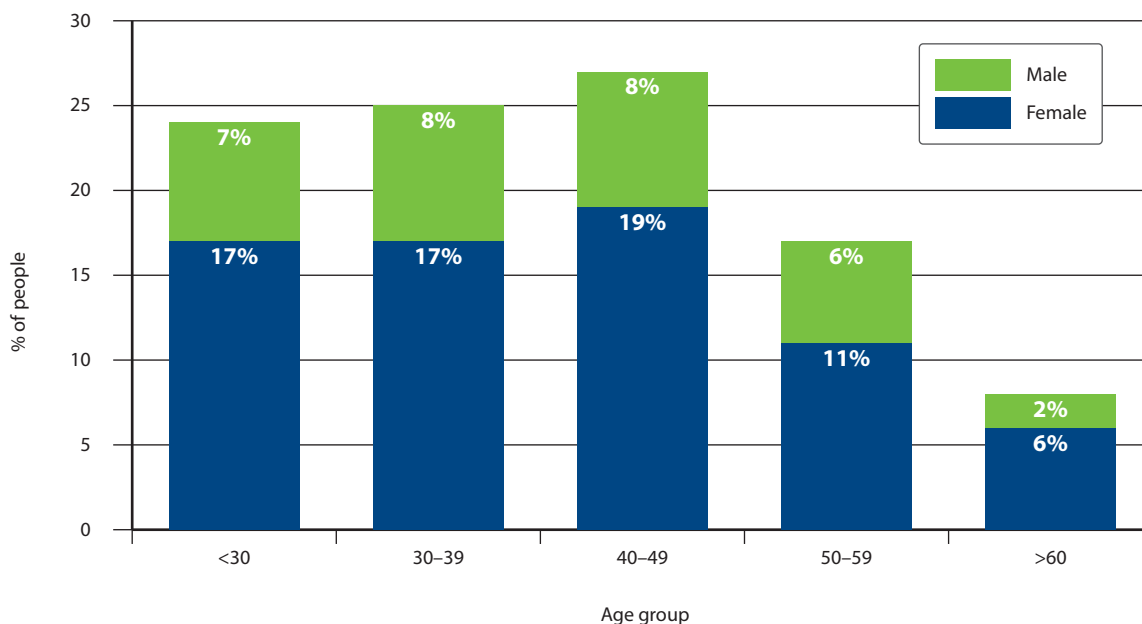
**Table 5** Employment Status

Employment Status	Number of people diagnosed	% of people diagnosed
Regular paid employment	193	56.2%
Self employed	18	5.2%
Looking after home/family	15	4.4%
Unemployed	17	4.9%
In formal education	18	5.2%
Retired	17	4.9%
Sick/disabled (permanent or temporary)	21	6.1%
Other	2	0.6%
Unknown/not disclosed	43	12.5%
<b>Total</b>	<b>344</b>	<b>100.0%</b>

**Table 6** History of MS within Family

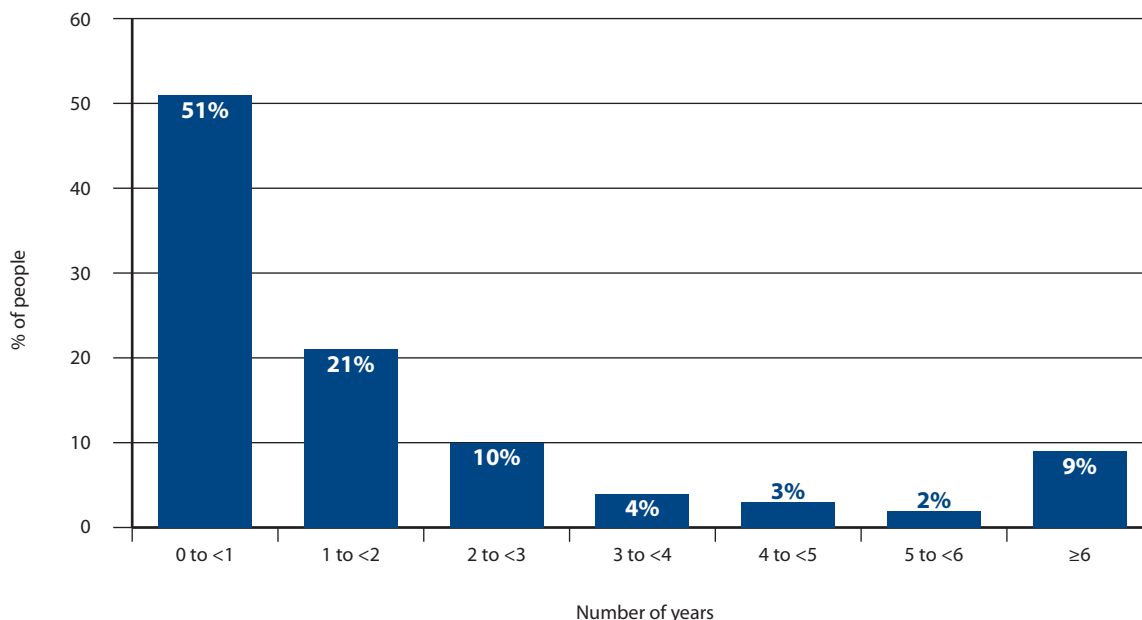
MS Family History	Number of people diagnosed	% of people diagnosed
History of MS in family	37	10.8%
No history of MS in family	244	70.9%
Unknown/not disclosed	63	18.3%
<b>Total</b>	<b>344</b>	<b>100.0%</b>

**Figure 1** What was the age and gender distribution of people who were diagnosed with MS in Scotland in 2010, at time of diagnosis?



Of the 344 people who were diagnosed with MS in Scotland in 2010, 30% (103) were male and 70% (241) were female. The median age of all people diagnosed was 40 years (IQR=30–50). There was no notable difference in age between males (median=40, IRQ=30–50) and females (median=41, IRQ=31–49) at time of diagnosis.

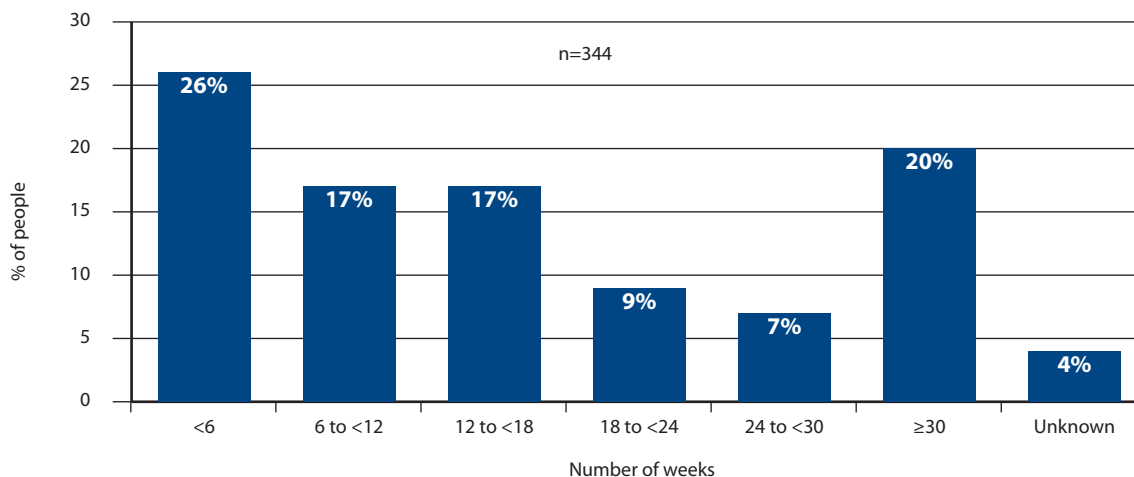
**Figure 2** How many years from first symptoms of MS to confirmed diagnosis?



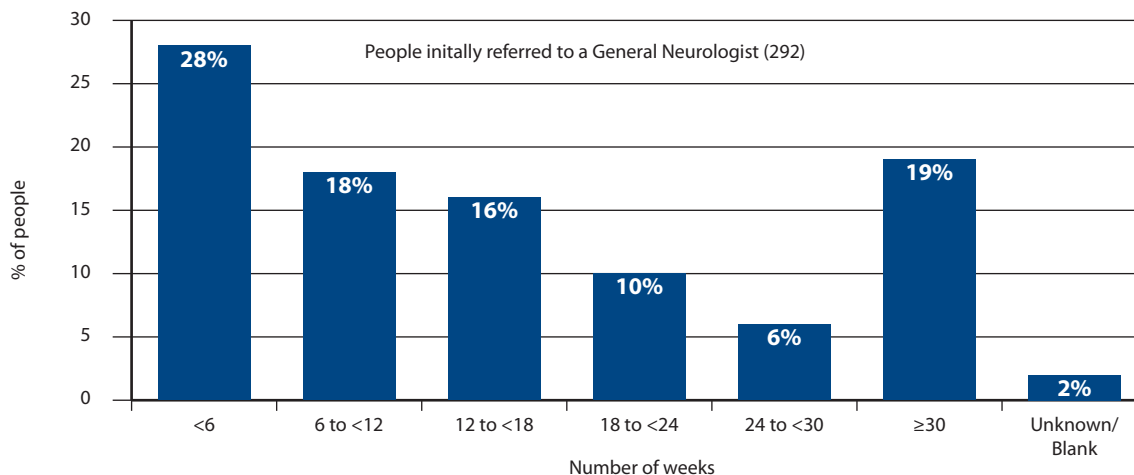
**Note** Figure excludes 116 cases where the month/year of first symptoms is unknown. The percentages presented in this figure are based on cases where the month/year of first symptoms is known (228).

MS can be complex in its nature and has a variety of symptoms; this means that in some cases it can take more than six years to have a diagnosis confirmed. 51% of people diagnosed with MS in 2010 were formally diagnosed within a year from the first sign of symptoms. For 33% of people, the date of first symptoms was unknown.

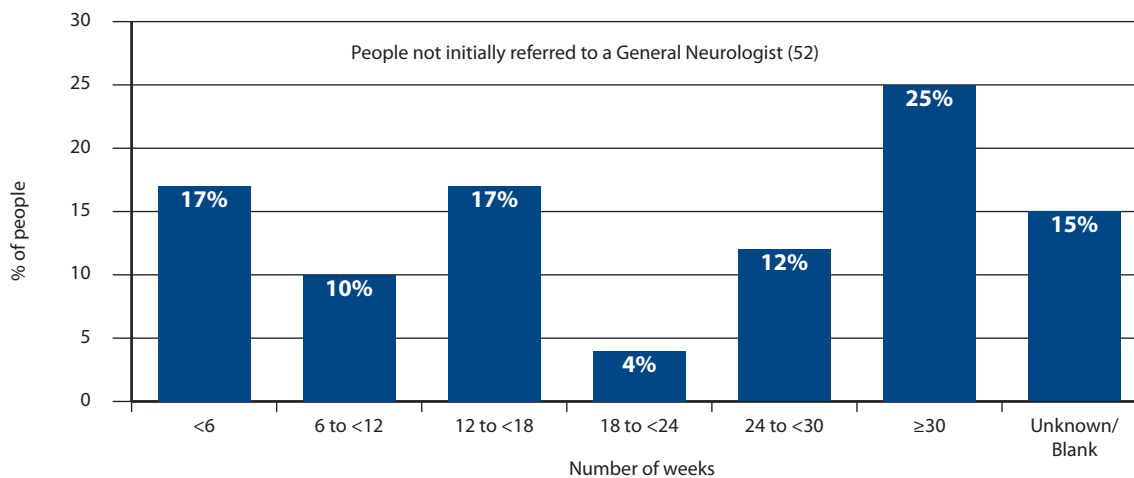
**Figure 3** How many weeks after referral to the hospital did it take to receive a confirmed diagnosis?



**Figure 3a** How many weeks did it take to receive a confirmed diagnosis after first examination following referral and did this vary according to the type of specialty that the person was referred to?

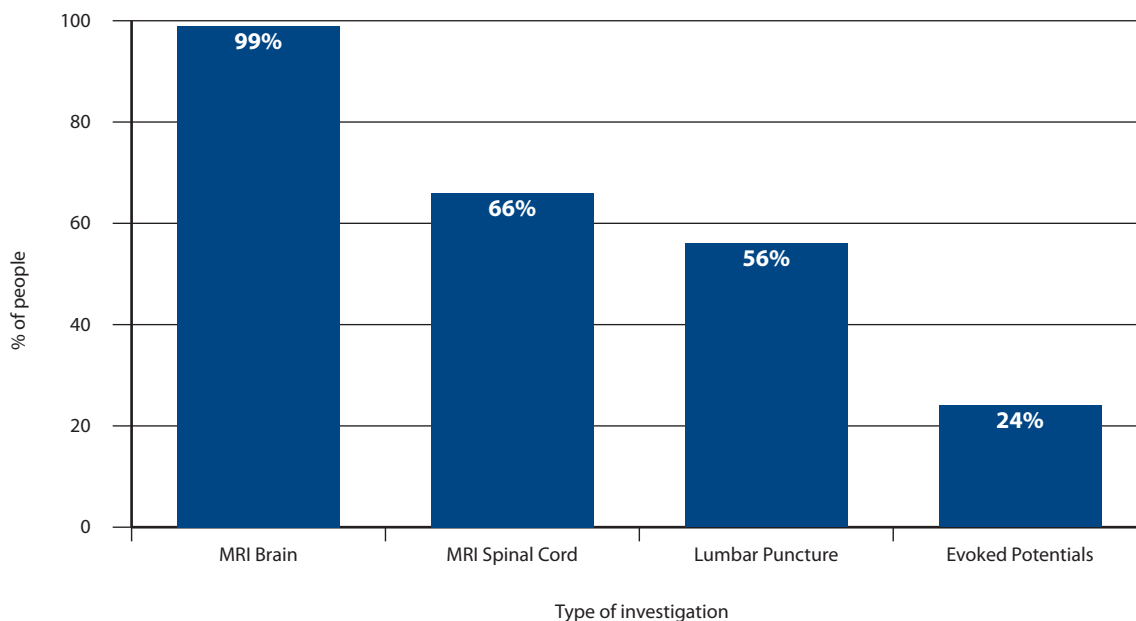


**Figure 3b** How many weeks after referral to hospital did it take to receive a confirmed diagnosis if you were not initially referred to a General Neurologist?



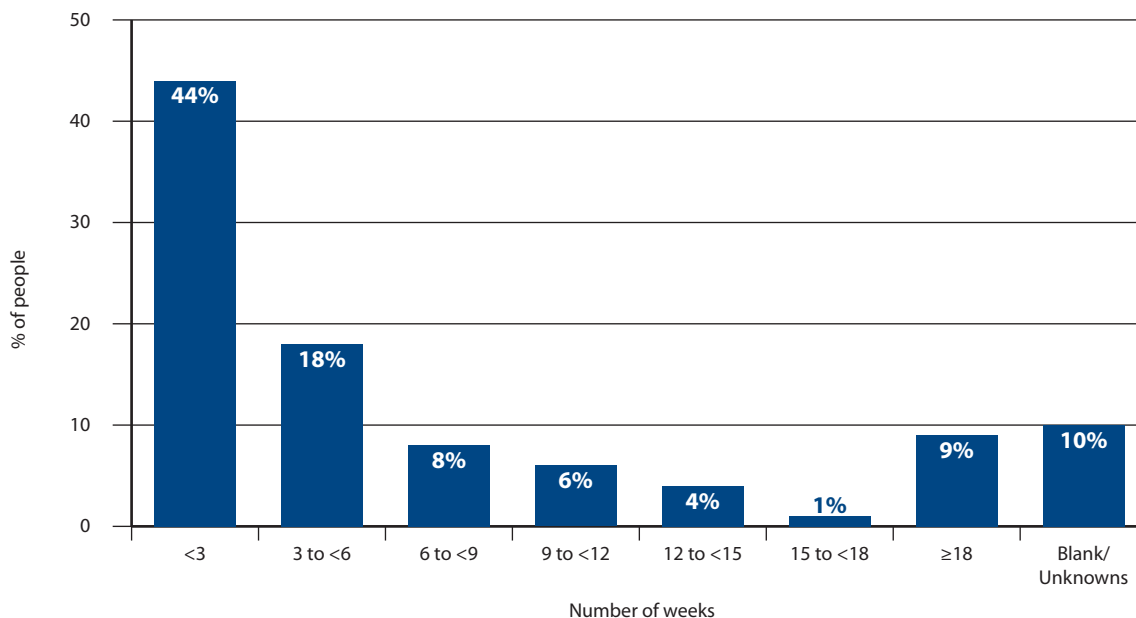
The graphs suggest that referral direct to neurology will lead to a quicker diagnosis with 62% being diagnosed within 18 weeks to referral as compared to 44% if to another specialty.

**Figure 4** How often was each type of investigation used to confirm MS diagnosis?



As MS is complex in its nature and has a variety of symptoms it is not easy to diagnose. There is no single diagnostic test and other conditions with similar symptoms may need to be ruled out before a final diagnosis can be made. Figure 4 shows that 99% of people received a brain MRI, two thirds received spinal MRI, just over half received a lumbar puncture and just under a quarter received evoked potentials.

**Figure 5** Where patient received a brain MRI (341 people), how many weeks after first examination following referral was it performed?



More than half of people received a brain MRI within 6 weeks of brain MRI request, 21% prior to referral to neurology, with a further 48% within six weeks of seeing a general neurologist, 84% by 12 weeks.

Following diagnosis, people with MS are offered a referral to a specialist MS nurse. Clinical Standards–October 2009, Neurological Health Services, Standard 15: Diagnosis of multiple sclerosis, 15.2 states that: ‘Contact with an MS clinical nurse specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of diagnosis.’ Figures 6 and 7 provide details of the length of time it took for people diagnosed with MS to be referred and to have first contact with a MS Nurse.

**Figure 6** How many weeks after confirmed diagnosis was person referred to MS nurse?

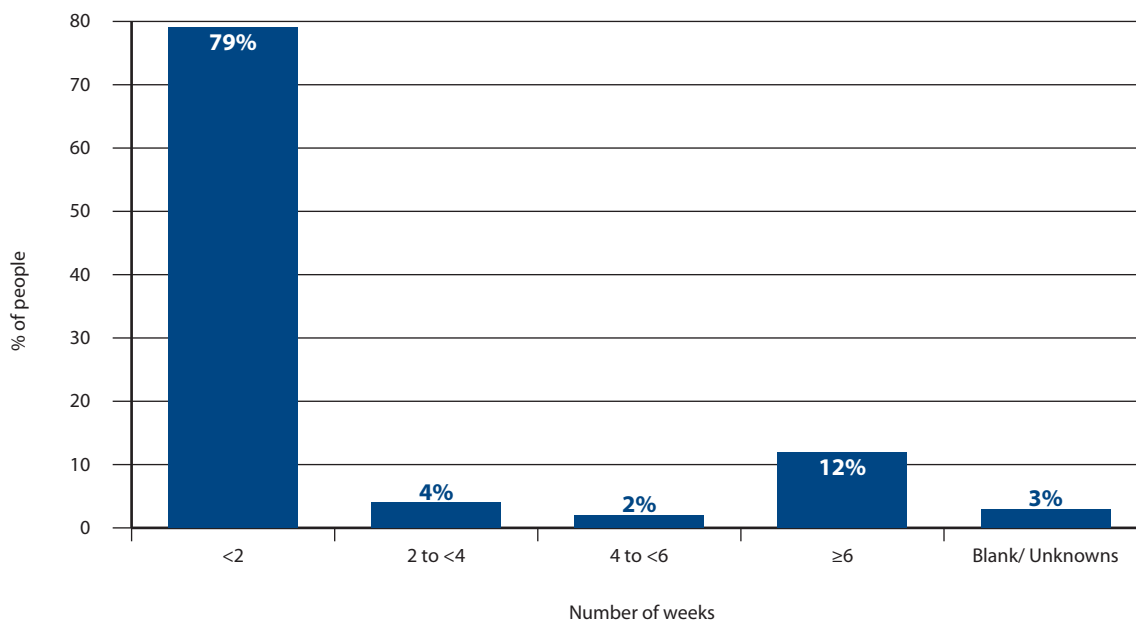
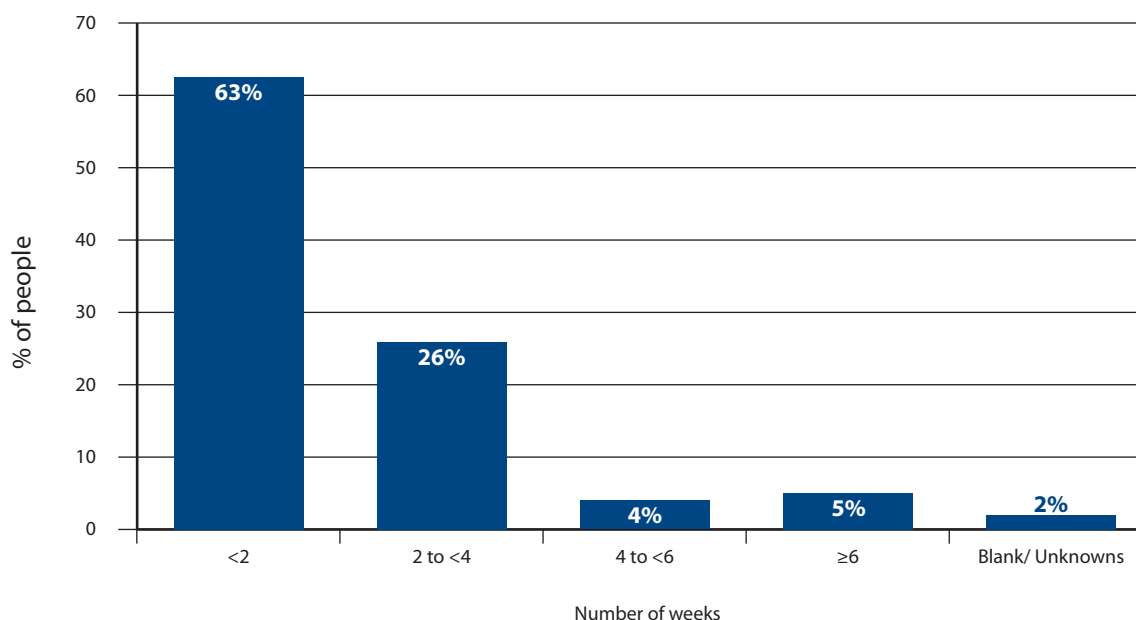
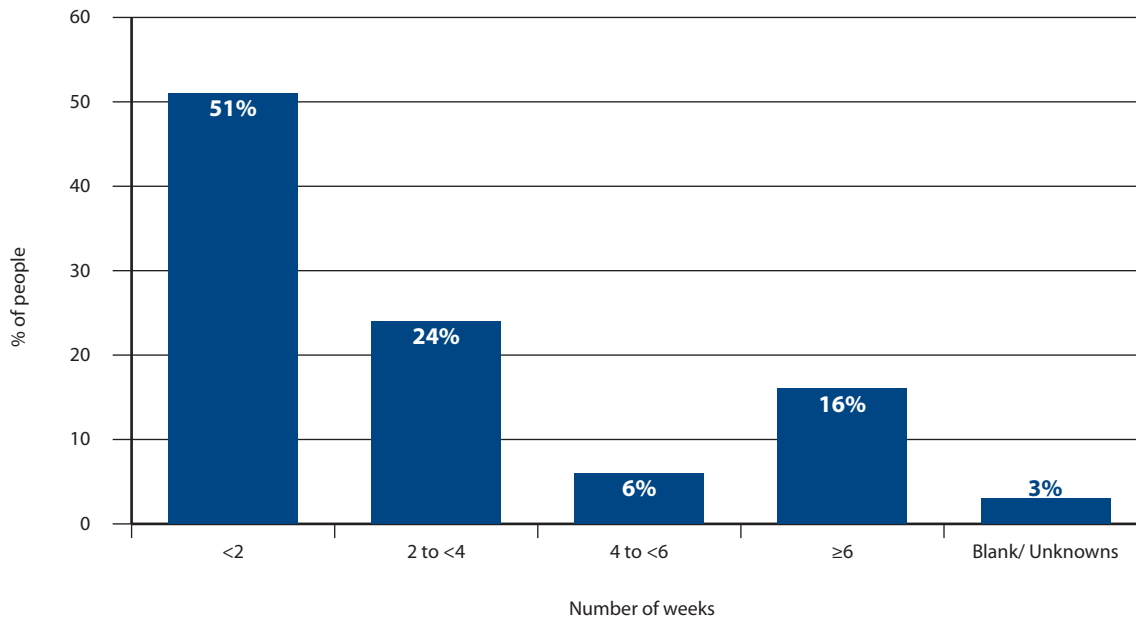


Figure 6 shows that 18% of referrals are received more than two weeks after date of diagnosis of MS.

**Figure 7** How many weeks from MS Nurse receiving referral to person being contacted by MS nurse?



**Figure 8** How many weeks after confirmed diagnosis did person have first contact with MS nurse?



8% of people were supported by MS nurse specialist prior to be given their diagnosis. 51% of people newly diagnosed with MS had contact with MS nurse specialist within two weeks of diagnosis, and 79% of all people being contacted within 6 weeks of diagnosis.

Steering Group	Role	
Belinda Weller (Chair)	Clinical Lead	Western General Hospital
Lynn Cherry	MS Nurse Specialist	Institute of Neurological Science
Ed Holloway	Head of care and services research	MS Society UK
Jane Lough	MS Physiotherapist	Institute of Neurological Science
Paul Mattison	Clinical Lead	Douglas Grant Rehabilitation Centre
Margaret Ann Macleod	Clinical Lead	Aberdeen Royal Infirmary
Nicola Macleod	MS Nurse Specialist	Western General Hospital
David McNiven	Director	MS Society Scotland
George Mowat-Brown	Patient Representative	
Christian Neumann	Clinical Lead	Forth Valley Royal Hospital
Colin O'Leary/ James Overell	Clinical Lead	Institute of Neurological Science
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Lance Sloan	Clinical Lead	Cameron Hospital
Uwe Spelmeyer	Clinical Lead	Victoria Hospital
Ann Stewart	MS Nurse Specialist	Raigmore Hospital
Hester Ward	Medical Director	Information Services Division, NHS National Services Scotland

NHS Health Board	Hospital	Lead Consultant
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Paul Mattison
Borders	Borders District General	David Simpson
Dumfries & Galloway	Dumfries General Royal Infirmary	Locum
Fife	Cameron Hospital	Lance Sloan
	Victoria Hospital	Uwe Spelmeyer
Forth	Forth Valley Royal Hospital	Christian Neumann
Grampian	Aberdeen Royal Infirmary	Margaret Ann Macleod
Greater Glasgow & Clyde	Institute of Neurological Science	Colin O'Leary/ James Overell
Highlands	Raigmore Hospital	Bethany Jones
Lothian	Western General Hospital	Belinda Weller (Chair)
Tayside	Ninewells Hospital	Johnathan O'Riordan
	Perth Royal Infirmary	Johnathan O'Riordan

NHS Health Board	Hospital	Register Co-ordinator
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	Victoria Hospital	Uwe Spelmeyer
Forth	Forth Valley Royal Hospital	Hazel Gaylor
Grampian	Aberdeen Royal Infirmary	Rose Johnston
Greater Glasgow & Clyde	Institute of Neurological Science	Lynn Cherry
Highlands	Raigmore Hospital	Ann Stewart
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## Further Information

Further information can be found on the [Scottish MS Register website](#).



# Useful Links

[MS Society—What is MS?](#)

[The Scottish MS Register](#)

[MS Society](#)

[ISD Scotland](#)

[MS Society—What is the UK Register?](#)

[MS Society—UK MS Register Portal](#)

## What is ...?

### 1. ...Multiple sclerosis

[Multiple sclerosis](#) is the result of damage to myelin—a protective sheath surrounding nerve fibres of the central nervous system. The central nervous system comprises the brain and spinal cord. Together with the nerves connecting to the rest of the body, they form the body's communication network.

In the earlier stages of MS, the central nervous system can often repair areas of damaged myelin or reroute messages via different pathways of neurons thereby avoiding the damaged areas. This explains why episodes of symptoms (relapses) can be followed by weeks, months or even years when symptoms improve or disappear (remission). However, if the area of damage becomes too large, communication with that specific part of the central nervous system may become permanently blocked.

For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

### 2. ...Magnetic resonance imaging (MRI)

The MRI scanner is a piece of equipment that uses strong magnetic fields to create a detailed image of the brain and spinal cord. MRI scans show changes in the central nervous system in over 95 per cent of people with MS.

### 3. ...Lumbar puncture

This is carried out under a local anaesthetic and involves a needle being inserted in to the lower back. A small sample of the fluid that flows around the brain and spinal cord is taken and tested. Most people with MS have abnormal proteins in this fluid, showing that the immune system has been at work in the central nervous system. A lumbar puncture tends only to be carried out if a diagnosis of MS has not been confirmed by other tests.

### 4. ...Evoked potentials

This involves testing the time it takes the brain to receive messages. Small electrodes are placed on the head to monitor how the brain waves respond to what is seen or heard. If there is damage to the myelin in the brain messages and responses will be slower or weaker.