

Scottish Multiple Sclerosis Register National Report 2013

Information relating to 01.01.2010–31.12.2012



Scottish
MS Register

Scottish MS Register Contact List

Dr Belinda Weller

Chair of Steering Group, Scottish Multiple Sclerosis Register Project

Email: belinda.weller@luht.scot.nhs.uk

Tel: 0131 537 2403

Anita Pritchard

Clinical Coordinator, Scottish Multiple Sclerosis Register Project

Healthcare Audits, National Services Scotland

Email: anita.pritchard@nhs.net

Tel: 0141 282 2212

Amanda Gilmour

Information Analyst

Healthcare Audits, National Services Scotland

email: amanda.gilmour@nhs.net

Tel: 0141 282 2135

Stuart Baird

Service Manager

Healthcare Audits, National Services Scotland

email: s.baird@nhs.net

Tel: 0131 275 6043

Useful Websites for further information

[The Scottish MS Register](http://www.isdscotland.org/Health-Topics/Scottish-Healthcare-Audits/Scottish-Multiple-Sclerosis-Register/)

<http://www.isdscotland.org/Health-Topics/Scottish-Healthcare-Audits/Scottish-Multiple-Sclerosis-Register/>

[ISD Scotland](http://www.isdscotland.org/)

<http://www.isdscotland.org/>

[Healthcare Improvement Scotland](http://www.healthcareimprovementscotland.org/)

<http://www.healthcareimprovementscotland.org/>

[MS Society](http://www.mssociety.org.uk/about_ms/index.html)

http://www.mssociety.org.uk/about_ms/index.html

[MS Society—What is MS?](http://www.mssociety.org.uk/support_and_services/free_publications/what_is_ms.html)

http://www.mssociety.org.uk/support_and_services/free_publications/what_is_ms.html

[MS Trust—What is MS?](http://www.mstrust.org.uk/information/aboutms/whatisms.jsp)

<http://www.mstrust.org.uk/information/aboutms/whatisms.jsp>

[MS Society—What is the UK Register?](http://www.mssociety.org.uk/get-involved/msregister)

<http://www.mssociety.org.uk/get-involved/msregister>

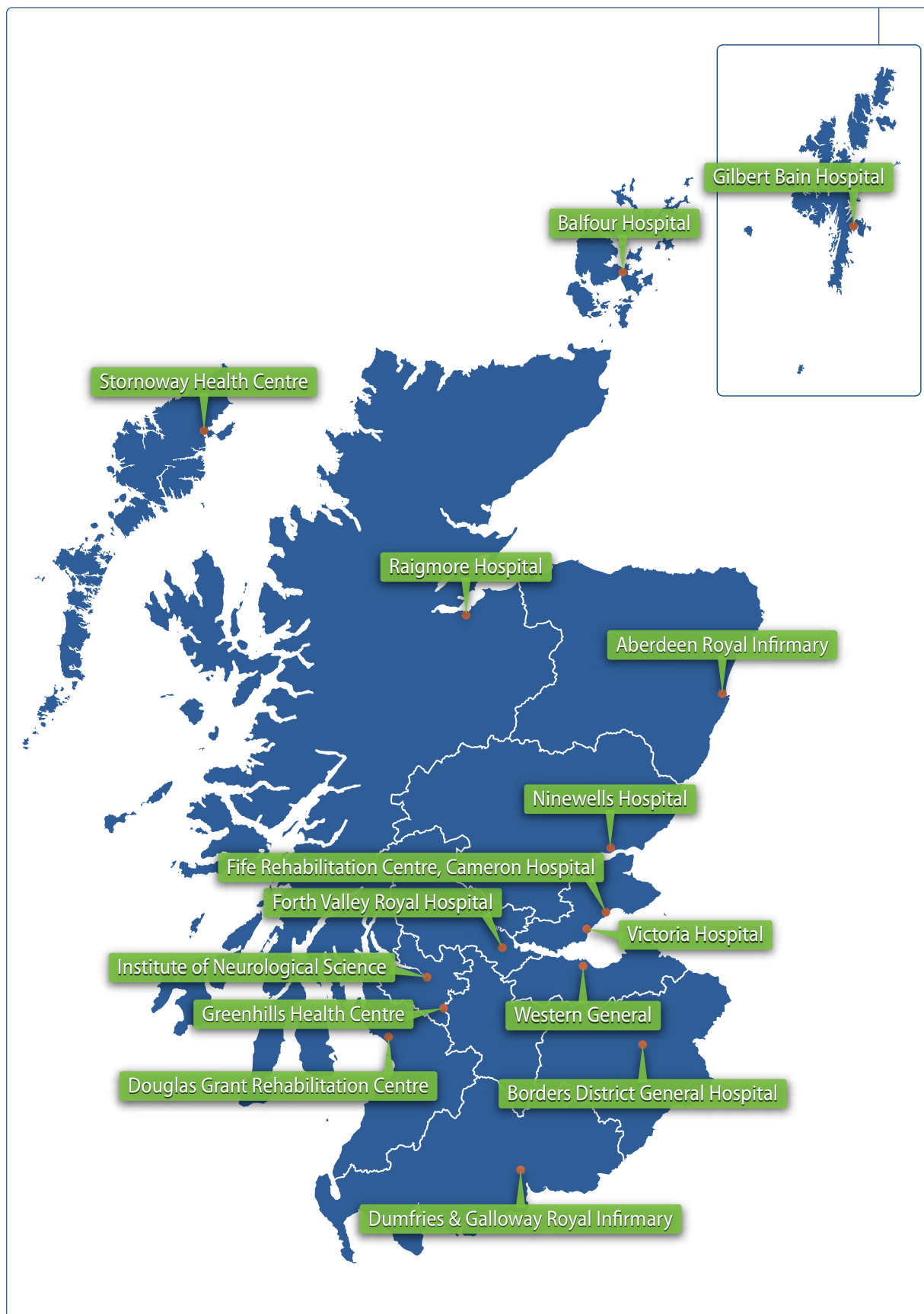
[MS Society—UK MS Register Portal](http://www.ukmsregister.org/Portal/Homel)

<http://www.ukmsregister.org/Portal/Homel>

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Map of Scotland showing all MS service providers by NHS Boards who contribute to the 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 / Health Centre	Lead Consultant
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Paul Mattison (Acting Chair)
Borders	Borders District General	David Simpson
Dumfries & Galloway	Dumfries General Royal Infirmary	Ondrej Dolezal
Fife	Cameron Hospital Victoria Hospital	Lance Sloan Uwe Spelmeyer
Forth Valley	Forth Valley Royal Hospital	Christian Neumann
Grampian	Aberdeen Royal Infirmary	Margaret Ann MacLeod
Greater Glasgow & Clyde	Institute of Neurological Science	James Overell Stuart Webb
Highland	Raigmore Hospital	Bethany Jones
Lanarkshire	Greenhills Health Centre	James Overell
Lothian	Western General Hospital	Belinda Weller (Chair)
Orkney	*	*
Shetland	Gilbert Bain Hospital	James Unsworth
Tayside	Ninewells Hospital Perth Royal Infirmary	Johnathan O’Riordan Johnathan O’Riordan
Western Isles	**	Saif Razvi

* for information, please contact Moira Flett, MS Nurse Specialist

** diagnosis made by General Neurologist from Institute of Neurological Science, Glasgow

NHS Health Board	Hospital / Health Centre	Register Co-ordinator
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Jacque Downs
Borders	Borders District General	Lorna Rogerson
Dumfries & Galloway	Dumfries General Royal Infirmary	Liz Clark
Fife	Cameron Hospital	Debbie McCallion
Forth Valley	Forth Valley Royal Hospital	Hazel Gaylor
Grampian	Aberdeen Royal Infirmary	Mairi Maguire
Greater Glasgow & Clyde	Institute of Neurological Science	Lynn Cherry
Highland	Raigmore Hospital	Ann Stewart
Lanarkshire	Greenhills Health Centre	Mhairi Coutts
Lothian	Western General Hospital	Nicola Macleod
Orkney	Balfour Hospital	Moira Flett
Shetland	Gilbert Bain Hospital	Dorothy Storey
Tayside	Ninewells Hospital Perth Royal Infirmary	Pamela Walker Pamela Walker
Western Isles	Stornoway Health Centre	Rachel Morrison

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

Introduction

The Scottish MS Register has been established to collect information about people with a new diagnosis of MS since 1st January 2010; General Neurologists and MS clinical teams provide the data on which this report is produced. This information provides epidemiological data and will also develop an increased focus on health improvement. The register will also facilitate and stimulate research to help to understand the reasons for the very high incidence and prevalence rates of multiple sclerosis in Scotland.

The responsibility for the oversight of the register including maintenance of reporting standards, adherence to aims, objectives and reporting of results rests with the register Steering Group, with multidisciplinary representation from all of the Health Boards in Scotland. The Steering Group meets regularly throughout the year to review the progress and direction of the register in achieving its aims and objectives. Presentations of the data at both national and international meetings have been made. It is hoped that further work will be undertaken comparing the Scottish MS Register information with previous epidemiological studies and current improvement work in the management of people with MS.

I would like to thank all of the clinicians who continue to give their time and effort to report information about newly diagnosed people with MS to the Scottish MS Register and I am optimistic that this unique Scottish endeavour will provide information which will be used to improve the quality of life of people with MS.

Paul Mattison

Acting Chair of Scottish MS Register Steering Group

Organisational structure of the Scottish MS Register

The Scottish MS Register is a national register within the Scottish Healthcare Audits programme at the Information Services Division (ISD) of NHS National Services Scotland (NSS). The register has its own Steering Group of key stakeholders who provide strategic direction, epidemiological and clinical input to the register team, and ensure the achievement of the optimum use of the data.

The organisation structure of the Scottish MS Register is:

- **Dr Belinda Weller**—Chair of the Steering Group
- **Dr Paul Mattison**—Acting Chair of the Steering Group from September 2012
- **Anita Pritchard**—Clinical Co-ordinator
- **David Readhead**—Information Analyst until 31st October 2012
- **Amanda Gilmour**—Information Analyst from 31st October 2012

Patient Representative Group of the Scottish MS Register

Multiple Sclerosis results from damage to the protective sheath of myelin that surrounds the nerve fibres of our brain and spinal chord. MS presents itself in a multitude of ways and of differing severity in those who are afflicted by it. For sixty years it has been accepted that there are more people with MS in Scotland per capita than anywhere else in the world—with the greatest occurrence of these being in the Northern Isles. It is, however, only with this collection of data at a national level, and the formation of the Scottish MS Register from the beginning of 2010, that we are starting to be able to ascertain reliably where these people are, what clinical and other support is required, and whether services are meeting published national standards.

The Scottish Government has recognized and supported the need for robust national datasets to enable both individuals and organizations to assess and monitor the quality of care that is being provided against evidence-based standards and to ensure that this is compliant with the published guidelines. The Scottish MS Register was established to develop this reliable national database for MS which is now being used to develop and improve patient services at a local level. For it to be seen to be doing so, it is vital that the register is able to provide robust data that can assist in answering many questions that are important to patients and their carers as well as the more general clinical community. The project continues to invest time and effort to ensure that data is as complete and accurate as possible. This has been facilitated through the support and participation of consultants who deal with, or have an interest in MS, in combination with the MS Nurse specialists who are co-ordinating the collection of the data.

As a small example of the improvement of the service provision that was identified for last year's report was the procedural delays within the clinical reporting system. This has allowed MS Nurse specialists to highlight to clinical staff where these delays were occurring and to emphasize to the administration that the sooner they receive the referral, the sooner the requested support from the MS team can be put in place.

The register is now progressing from principally recognizing the distribution of MS across Scotland to putting the fruits of this data collection into more practical avenues for patients through the further development of the equitable provision of services that are available to them — wherever in the nation they live. To ensure that this embraces the concerns of as many people with MS and their carers as is feasible, the patient representative group is soon to be expanded.

With the help of neurologists, MS Nurse specialists and our patient representative group the register is moving forward with the aim of improving health care services for people with MS.

George Mowat-Brown
Chair MS Patient Representative Group

Progress

The Scottish MS Register (SMSR) is part of Information Services Division (ISD) and started to collect data on 1st January 2010. The register relies on clinicians and MS nurse specialists to identify and submit information about people with a confirmed diagnosis of MS.

The Steering group directs the activities of the Scottish MS Register. In 2013 the register focused on:

- Investigating potential areas of under reporting as there are still concerns amongst the SMSR Steering Group that this may be the case in certain Health Boards. Meetings and telephone conferences have been carried out in March and June with the lead clinicians and MS nurse specialists at these units resulting in the development of a local plan to be reviewed at the end of September. It is hoped that the efforts introduced earlier this year will improve the number of new people with MS being registered by General Neurologists to the register.
- Establishment of routine reporting of the NHS HIS Neurological Standards Standard 15.2. This report monitors the proportion of patients who are contacted by an MS nurse within 2 weeks of diagnosis. Reports are produced every 3 months and incorporate and monitor the referral process from time of diagnosis to contact by the MS nurse at a national, local and individual level. People with MS whose care does not meet the standard are identified for local review (see page 10 to 12). Information will be utilised at a national level in the annual report and is shared with National Neurology Advisory Group.
- In an effort to verify the numbers the MS register wish to compare its database with Scottish Morbidity records (SMR) and Practice Team Information (PTI) held within ISD. This would allow comparison between the data sets for matches and potential missing cases of people with a confirmed diagnosis of MS since 2010.

This work is one of the attempts to search for confirmation of case ascertainment of people with MS who fit the Register's criteria and are not on the register. Once identified quality assurance checks will be carried out by the team. It is hoped the linkage will improve the quality of the register data, and therefore help guide clinicians and policy makers to improve services and patient care.

Further work is underway to link the hospital outpatient information to the register information to report next year on Clinical Standards—October 2009, Neurological Health Services, Standard 16.1a: patients with Multiple Sclerosis have access to a review by an MS specialist service at least every 12 months.

Future improvements:

Review of aims and objectives by the steering group has been set for 12th of September 2013. Scottish MS Register has identified that there is a need to explore and develop, either through audit or research, current national and international standards and develop areas to improve patient management and services. This review will include:

- Equity of services, including equity of provision of Disease Modifying Treatments;
- Review of NHS HIS Neurological Standards relevant to MS;
- Development of time limited audits relevant to all people with MS, i.e. including incident and prevalent patients. Such audits will identify current practice at a national level and encourage and support clinical staff to review care at a local level;
- Development of a research portfolio; and

- Further development of the Patients' Reference Group to actively influence the direction of the register to improve patient care.

The MS Register has a Patients' Reference Group which is made up of people with MS and their carers from the whole of Scotland. The group ensures that the register considers a wide range of views and comments from people with MS and their carers; the group help guide the register to concentrate on how and what should be the focus in order to improve the healthcare service provision for people with MS. Their input to future direction of the register is essential to ensure that the information held by the register will facilitate learning, discussion and debate of the issues that are important to people with, and affected by, MS, as well as the professionals who are involved in providing advice, support, treatment and care.

Anita Pritchard

National Clinical Co-ordinator

Summary & Key points

The aim of Scottish MS Register is to establish the incidence of MS in Scotland, to interpret the implications of its demography and so enable service evaluation and improvement. The system for reporting people with a new diagnosis of MS to the Scottish MS Register is improving year on year; the first national report in 2011 recorded 344 people with a new diagnosis of MS, in this report the number for 2010 is now 418.

Data on all known patients registered by a Consultant Neurologist with a new definite diagnosis of MS from 1st January 2010 to 31st December 2012 in Scotland were collected using a standard proforma (www.msr.scot.nhs.uk/Documents/MS%20Incidence%20Form%20-v2_10_11.pdf), which incorporated the patient journey from referral to diagnosis, including referral to an MS Nurse specialist. Analysis of the data was undertaken, including outline data checks to ensure data quality and validity.

The third year of information shows:

On 31st March 2013, 1237 people were registered, 418 with a date of diagnosis in 2010, 388 in 2011 and 431 in 2012. Twice as many women (290, 67%) as men (141, 33%) were diagnosed with MS in 2012.

In 2012, 8% of people were supported by an MS Nurse specialist prior to be given their diagnosis. 47% of people newly diagnosed with MS had contact with a MS Nurse specialist within two weeks of diagnosis. This is an 8% decrease from 2011.

Delays in referral to MS nurse and/or delays in MS nurse receiving referral may be accountable for the 8% decline in people newly diagnosed with MS being contacted by an MS nurse specialist within 2 weeks of diagnosis. MS team should examine delays in the referral process locally to target solutions or resources.

Targeting individual steps may actually realise greater improvement in the referral process. The key result is that in 2012 nationally the time response within 2 weeks was very effective (85%) once the MS Nurse specialist was aware that there was a person newly diagnosed with MS who wished to be contacted. From 31st July 2012 this information is reported to the MS Clinical Lead and MS Nurse Specialist every 3 months.

Linkage of information from the Scottish MS Register and information collected by Health Boards in Scotland (www.isdscotland.org/Products-and-Services/Data-Quality) regarding hospital admissions has resulted in a reduction in the amount of information collected by clinical staff leading to a simpler registration form.

Results

Section 1 Introduction to NHS HIS Neurological Standards

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 1 and 2 provide details of the length of time it took for people diagnosed with MS to be referred and to have contact with a MS Nurse. (Whole Journey Time)

There are several steps in the process from the time a diagnosis of MS is given to the patient to the time the MS Nurse contacts the person. Targeting individual steps may actually realise greater improvement in the referral process. MS team should examine delays in the referral process locally to target solutions or resources.

These steps are:

- Figure 3—Time to referral: How many weeks after confirmed diagnosis was person referred to MS Nurse?
- Figure 4—Time to receive referral: How many weeks from referral to MS Nurse up to MS Nurse receiving referral?
- Figure 5—Time to Act: How many weeks from MS Nurse receiving referral to person being contacted by MS Nurse?

The key result is that nationally the time response within 2 weeks was very effective (85%) once the MS Nurse specialist was aware that there was a person newly diagnosed with MS who wished to be contacted.

Figure 1 Percentage of people with a new diagnosis of MS in Scotland contacted by MS Nurse within two weeks of confirmed diagnosis, meeting QIS standard 15.2 by Year

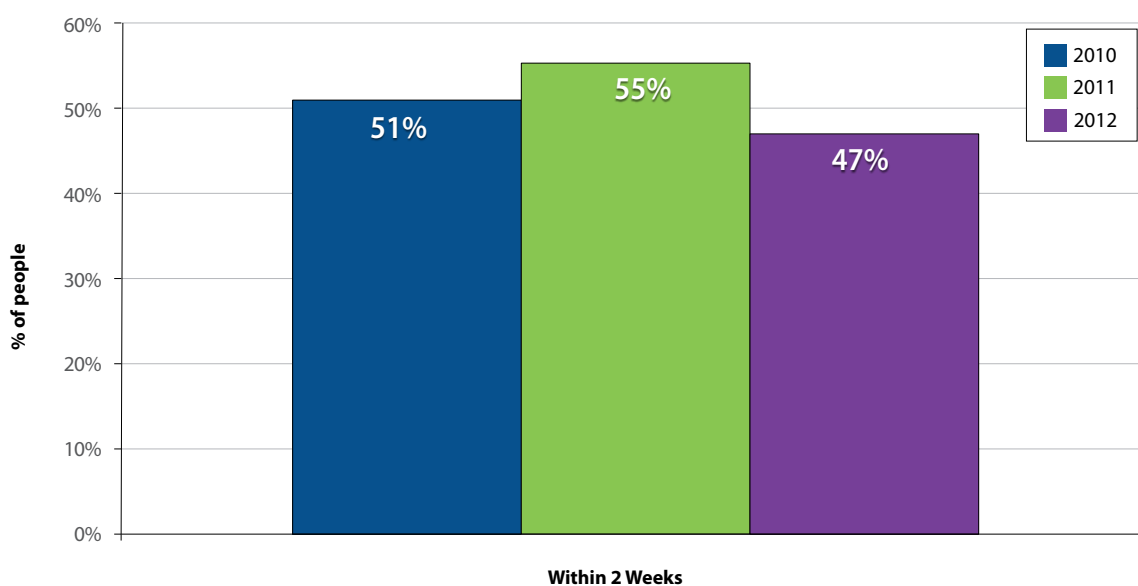
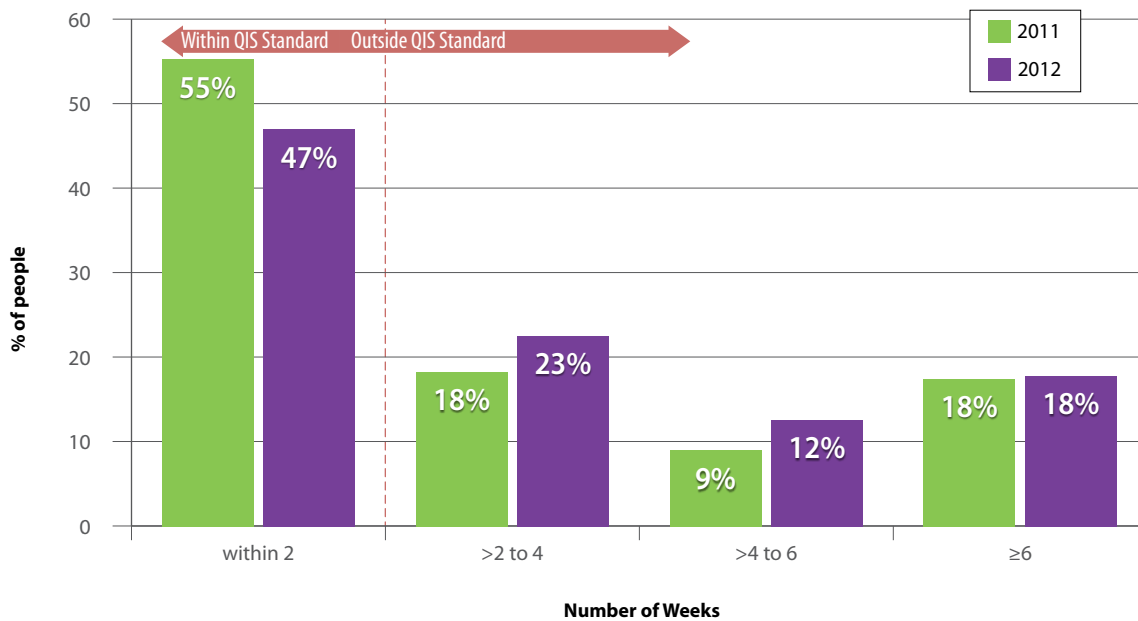


Figure 1 illustrates the percentage of people meeting QIS standard 15.2 in 2010 was 51%, in 2011 it reached its highest of 55%, and in 2012 it reached its lowest, falling to 47%.

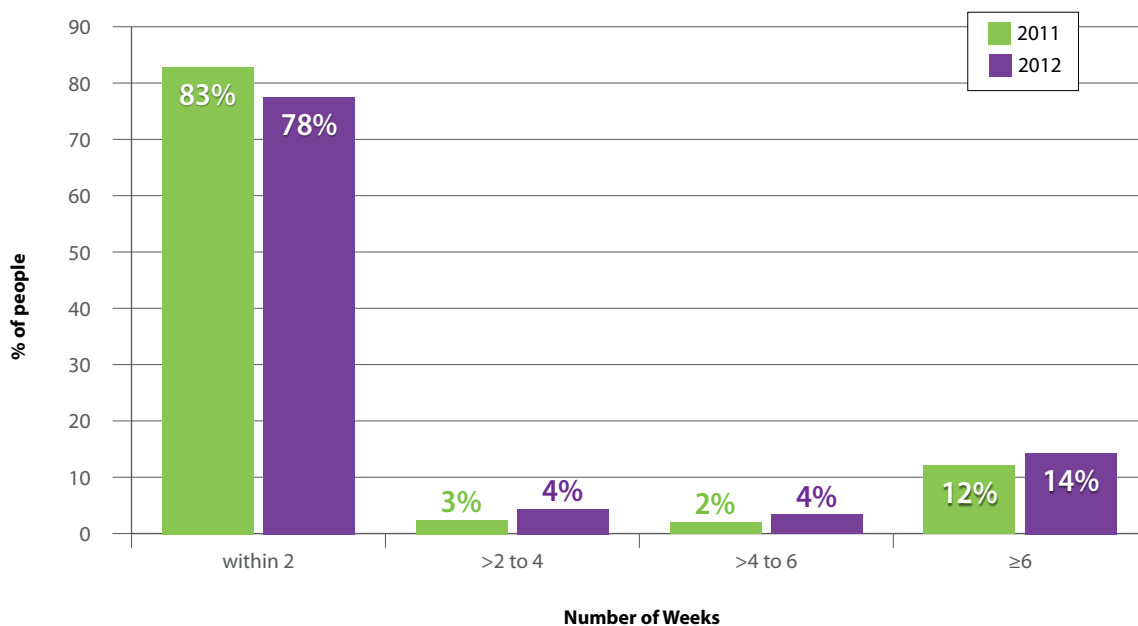
Figure 2 Percentage of people with a new diagnosis of MS in Scotland in 2011 and 2012, by number of weeks from confirmed diagnosis to first contact with MS Nurse



Seven patients were excluded due to their date of diagnosis or date of 1st contact with MS nurse being incomplete.

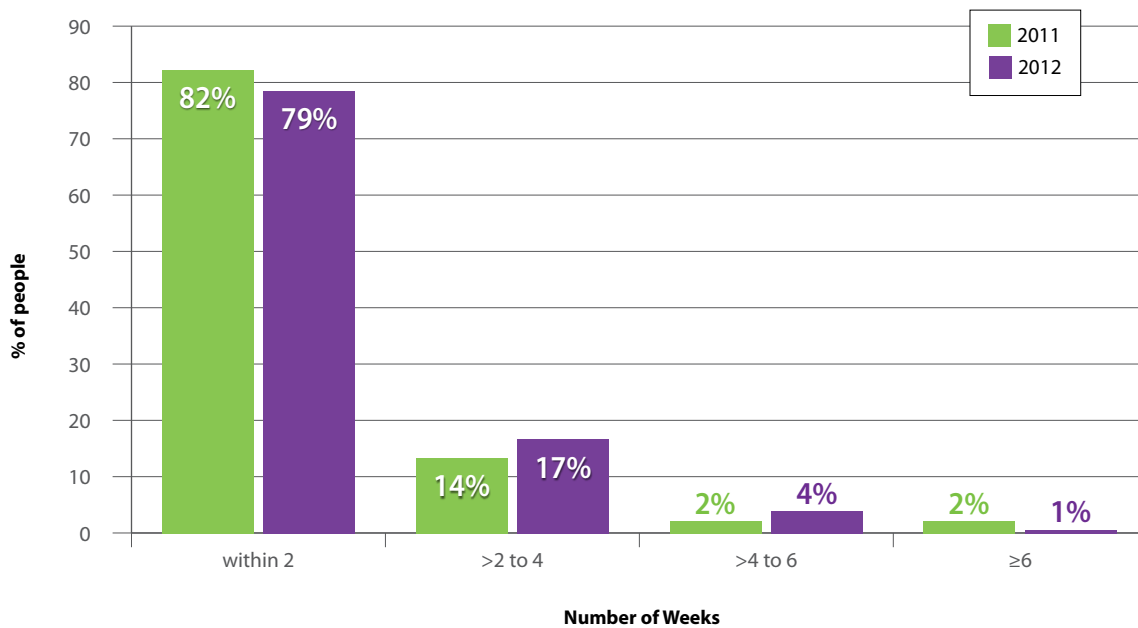
In 2012, 8% of people were supported by MS Nurse specialist prior to be given their diagnosis. 47% (Fig. 2) of people newly diagnosed with MS had contact with MS Nurse specialist within two weeks of diagnosis; this is an eight percent decrease from 2011. 82% of all people being contacted within 6 weeks of diagnosis.

Figure 3 Percentage of people with a new diagnosis of MS in Scotland in 2011 and 2012, by number of weeks from confirmed diagnosis to person being referred to MS Nurse



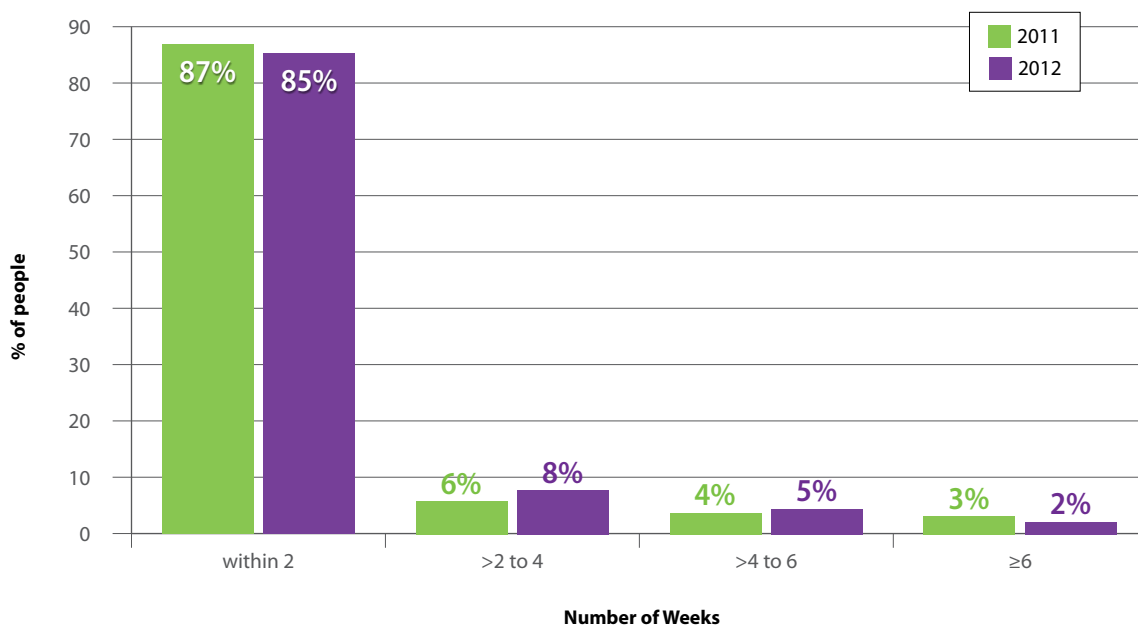
Nine patients were excluded due to their date of diagnosis or date of referral being incomplete.

Figure 4 Percentage of people with a new diagnosis of MS in Scotland in 2011 and 2012, by number of weeks from referral to MS Nurse receiving referral



19 patients were excluded due to the date their referral was sent and/or the date their referral was received by an MS nurse being incomplete.

Figure 5 Percentage of people with a new diagnosis of MS in Scotland in 2011 and 2012, by number of weeks from MS Nurse receiving referral to person being contacted by MS Nurse



18 patients were excluded due to the date their referral was received and/or date of 1st contact with MS nurse being incomplete.

Despite a drop in 8% of people meeting QIS standard 15.2 in 2012 (Fig. 2) the time response within 2 weeks was very effective (85%) once the MS nurse specialist was aware there was a person diagnosed with MS who wished to be contacted (Fig. 5). Consequently, delays in referral to MS nurse and/or delays in MS nurse receiving referral may be accountable for this decline. MS team should examine delays in the referral process locally to target solutions or resources.

Section 2 Demographics

A total of 1237 people were entered onto the Scottish MS Incidence Register from 1st Jan 2010 to the 31st Dec 2012 (Table 2). Throughout the remainder of this report the term 'people diagnosed' refers to people who were entered onto the Register from 01.01.2010. to 31.12.2012.

All Clinical Leads and MS Nurse Specialists within relevant Health Board verified the information provided in Tables 1 and 2. Fife, Lanarkshire and Ayrshire state that the figures are a true reflection of the people newly diagnosed with MS that are referred to their MS service. However, although the numbers being referred to the register are improving, there may be people who are diagnosed by a general neurologist and not referred to local services or reported to the register.

Table 1: Number of people with a new diagnosis of MS in Scotland in 2010, 2011, and 2012 reported by Health Board

Health Board	2010	2011	2012
Ayrshire and Arran	17	27	34
Borders	6**	7**	7**
Dumfries and Galloway	12	16	15
Fife	29	25	31
Forth Valley	17	23	25
Grampian	54	49	56**
Greater Glasgow	98	91	87
Highland	26	19	26
Lanarkshire	46	22	41
Lothian	59	54	48
Orkney	5	5	1**
Shetland	4	6	1**
Tayside	40	42	56
Western Isles	5	2**	3**
Total	418	388	431

** Data is incomplete due to collection problems.

Table 2: Number of people with a new diagnosis of MS in Scotland in 2010, 2011 and 2012, reported by Hospital from which register receives form

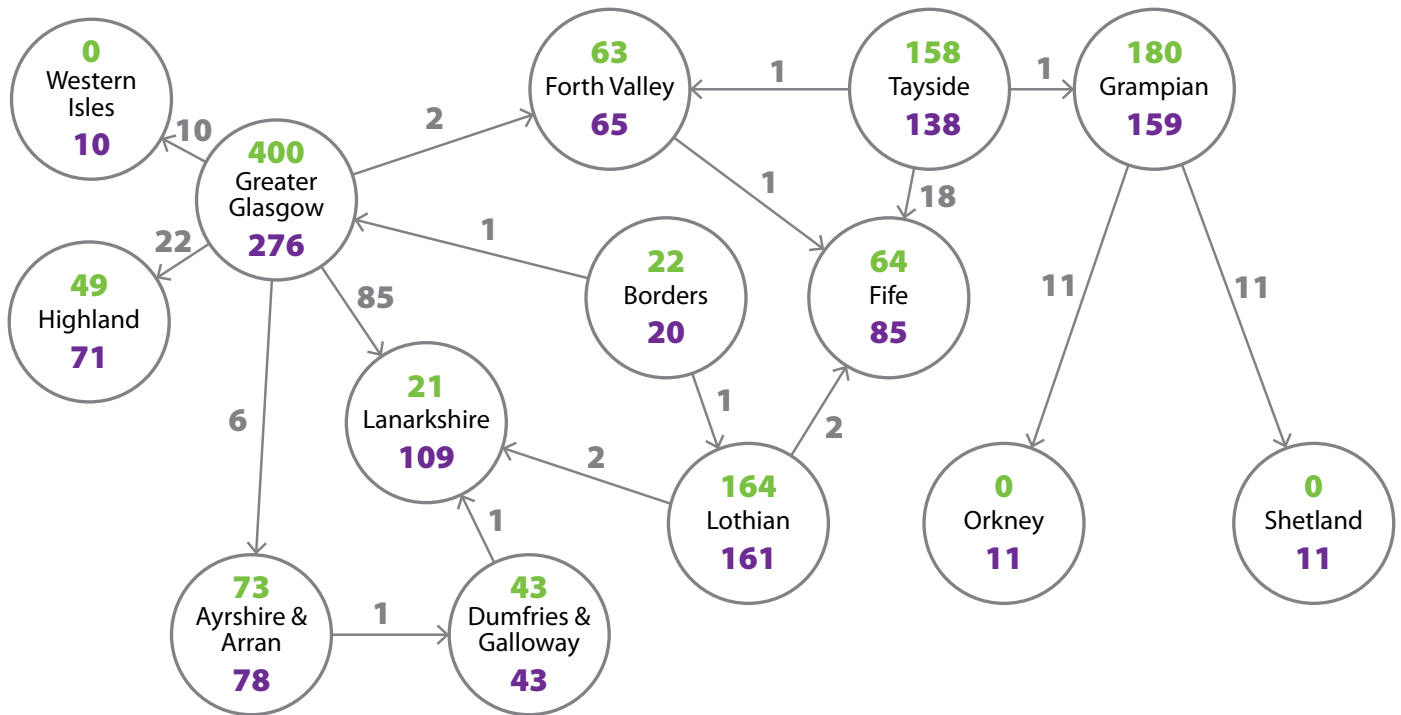
Health Board	Year of Diagnosis		
	2010	2011	2012
Aberdeen Royal Infirmary	63	60	57*
Ayrshire Central, Irvine	13	27	33
Borders District General	6*	8*	8*
Cameron Hospital, Fife	21	19	24
Dumfries General Royal Infirmary	12	15	16
Forth Valley Royal Hospital	17	23	23
Greenhills Health Centre, East Kilbride	0	3	18
Institute of Neurological Science, Glasgow	160	119	121
Ninewells Hospital, Dundee & Perth Royal Infirmary	47	47	64
Raigmore Hospital, Inverness	18	12	19
Western General Hospital	61	55	48
Total	418	388	431

** Data is incomplete due to collection problems.

Figure 6 Number of patients with a new diagnosis of MS from 01.01.2010 to 31.12.2012 by Health Board

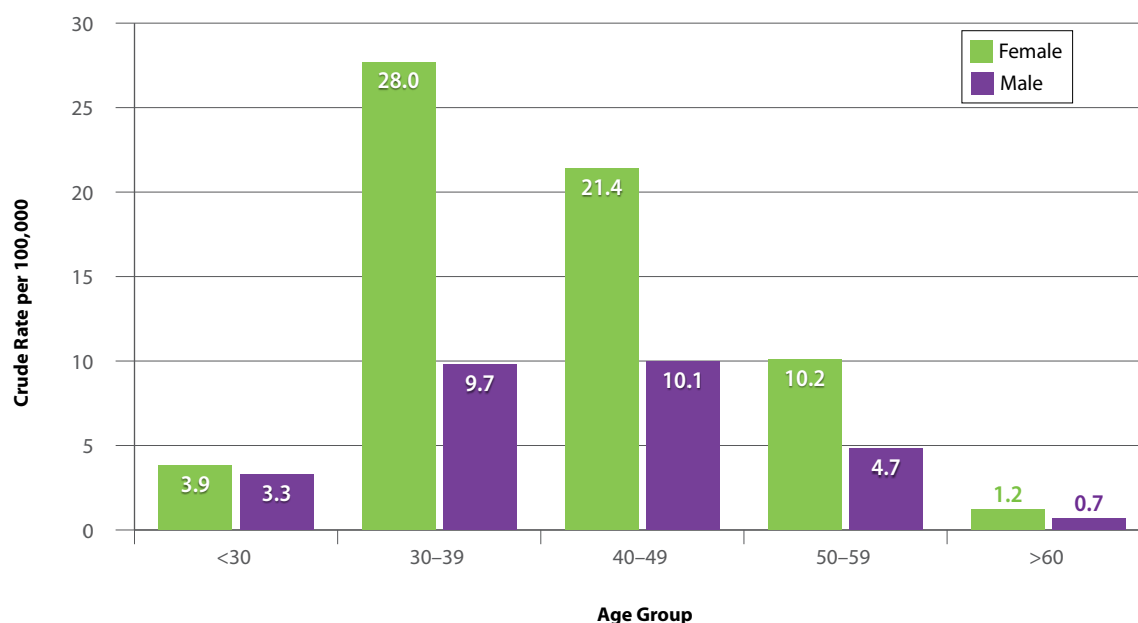
The Scottish MS Register criteria are that a patient has received a confirmed diagnosis of Multiple Sclerosis by a neurologist based on the McDonald or Poser criteria. The register does not include Clinically Isolated Syndromes or 'possibly MS'.

- Number of MS Forms received initially from Hospital in each Health Board
- Number of MS Patients recorded by Health Board based on residency at time of diagnosis



This flow chart shows that the majority of people being diagnosed with MS will be given the diagnosis from a General Neurologist from Greater Glasgow & Clyde Health Board. On the 31st of March 2013 a total of 400 MS forms was collected from the Institute of Neurological Science(INS), (NHS GG&C), 31% (124) patients reside in other Health Boards. These include Western Isles, part of Highlands, Lanarkshire and Ayrshire & Arran.

Figure 7 Crude rate per 100,000 of people with a new diagnosis of MS in Scotland in 2011, by gender and age at time of diagnosis



On 31st March 2013, 1237 people were registered, 418 with a date of diagnosis in 2010, 388 in 2011 and 431 in 2012. Twice as many women (290, 67%) as men (141, 33%) were diagnosed with MS in 2011.

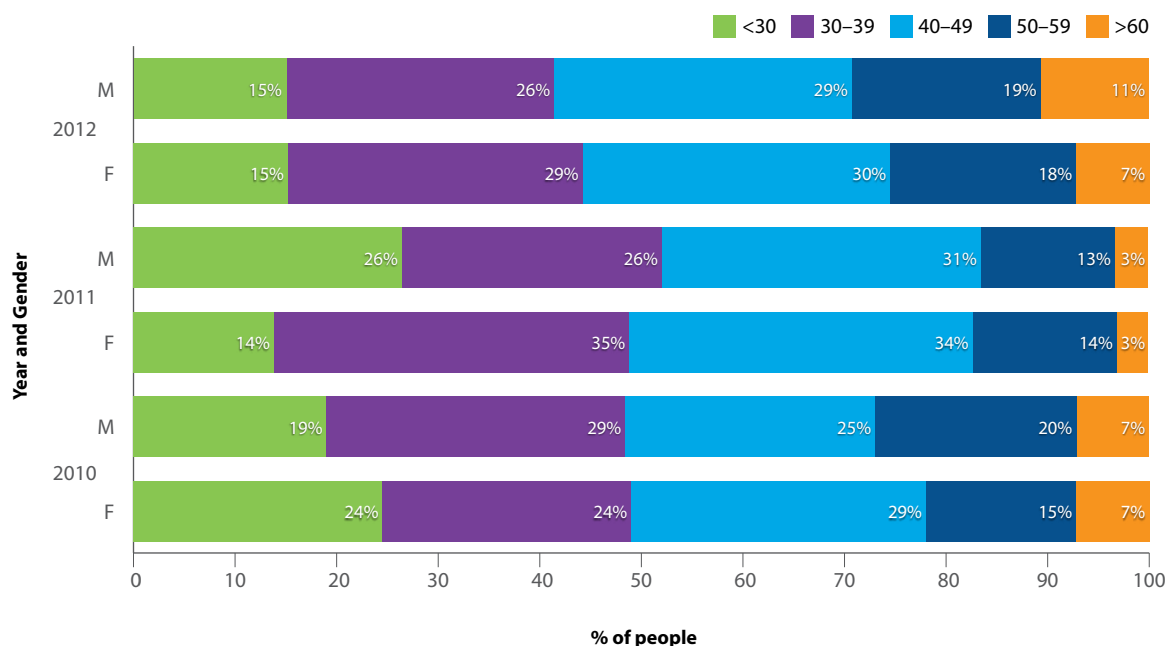
Table 3 Crude rate per 100,000 of people with a new diagnosis of MS in Scotland in 2011, by gender and age at time of diagnosis

Age Group	Male	Population	Crude Rate	Female	Population	Crude Rate
<30	32	968,082	3.3	36	929,260	3.9
30-39	31	318,364	9.7	91	325,447	28.0
40-49	38	376,780	10.1	88	410,415	21.4
50-59	16	340,505	4.7	37	361,573	10.2
>60	4	544,469	0.7	8	679,905	1.2
Unknowns	4			3		
Total	125	2,548,200	4.9	263	2,706,600	9.7

* Seven patients could not be reported because their date of birth and/or date of MS diagnosis was incomplete.

** Crude Rate is calculated as the number of Patients per 100,000 within the Population of each Age Group

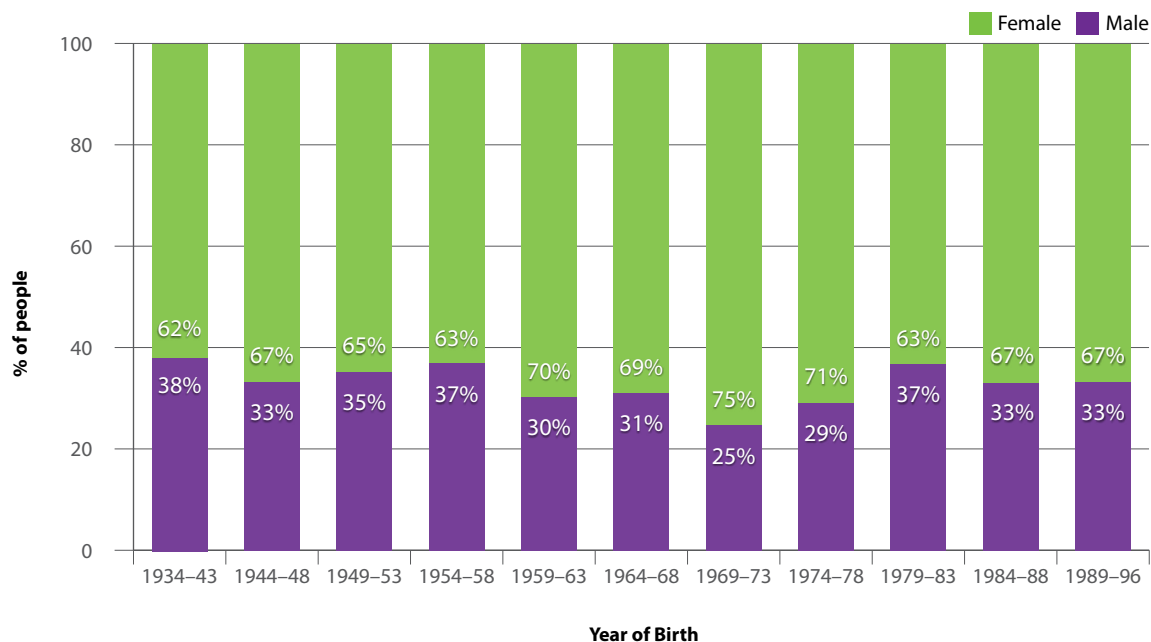
Figure 8 Percentage of people with a new diagnosis of MS in Scotland in 2010, 2011 and 2012, by gender and age at time of diagnosis



Ten patients were excluded due to their date of diagnosis or date of birth being incomplete.

Despite the growing number of people being referred to the register there are concerns that certain age groups are not accurately represented. The above Figure shows that the majority (over 52%) of both males and females were diagnosed between 30-49 years of age for all 3 years. This contradicts Rothwell & Charlton (1998) who found that MS diagnosis is most common in the 20-40 year age range, and infers that the youngest age group (<30) is under represented.

Figure 9 Percentage of people diagnosed with MS, by gender and year of birth



Seven patients were excluded due to their date of birth being incomplete.

An early study by Sutherland (1956) has indicated a ratio of one male to one female of people with a diagnosis of MS. The SMSR shows a consistent ratio of one male to two females.

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 4 to 7 present a summary of the demographic information collected for all people who were reported to the register as being diagnosed with MS in Scotland from 2010, 2011 and 2012. Please note the high number of cases for which information was not disclosed or was not known.

Since October 2011, completion of the following fields has been made optional: 'Country of Birth', 'Domestic Status', 'Employment Status' and 'History of MS in Family'. This information was provided for 90-100% of patients for: Ayrshire Central; Raigmore Hospital; Wishaw General Hospital; Ninewells Hospital; Perth Royal Infirmary; Falkirk & District Royal Infirmary; Forth Valley Royal Hospital; Dumfries & Galloway Royal Infirmary.

Table 4 Country of Birth

Country of Birth	2010		2011		2012		Total	
	Number	%	Number	%	Number	%	Number	%
Scotland	180	43.0%	148	38.1%	127	29.5%	455	36.8%
Other UK	15	3.6%	19	4.9%	12	2.8%	46	3.7%
Other	11	2.6%	12	3.1%	25	5.8%	48	3.9%
Unknown / not disclosed	212	50.8%	209	53.9%	267	61.9%	688	55.6%
Total	418	100%	388	100%	431	100%	1237	100%

Of the 549 patients who provided this information, it was found that 83% (455) stated that Scotland was their country of birth.

Table 5 Domestic Status

Domestic Status	2010		2011		2012		Total	
	Number	%	Number	%	Number	%	Number	%
Living alone	54	13.0%	53	13.7%	42	9.7%	149	12.0%
Living with spouse / partner	189	45.1%	145	37.4%	154	35.7%	488	39.5%
Living with family	115	27.6%	77	19.8%	26	6.0%	218	17.6%
Other	2	0.4%	0	0.0%	2	0.5%	4	0.3%
Unknown / not disclosed	58	13.9%	113	29.1%	207	48.0%	378	30.6%
Total	418	100%	388	100%	431	100%	1237	100%

Of the 859 patients who provided this information, it was found that 57% (488) currently resided with their partner/spouse.

Table 6 Employment Status

Employment Status	2010		2011		2012		Total	
	Number	%	Number	%	Number	%	Number	%
Regular paid employment	225	53.9%	214	55.2%	165	38.3%	604	48.8%
Self employed	19	4.6%	8	2.1%	0	0.0%	27	2.2%
Looking after home/family	23	5.5%	11	2.8%	6	1.4%	40	3.2%
Unemployed	23	5.5%	34	8.8%	33	7.7%	90	7.3%
In formal education	22	5.2%	8	2.1%	7	1.6%	37	3.0%
Retired	17	4.0%	6	1.5%	17	3.9%	40	3.2%
Sick/disabled (permanent or temporary)	28	6.7%	17	4.4%	5	1.2%	50	4.0%
Unknown / not disclosed	61	14.6%	90	23.2%	198	45.9%	349	28.2%
Total	418	100%	388	100%	431	100%	1237	100%

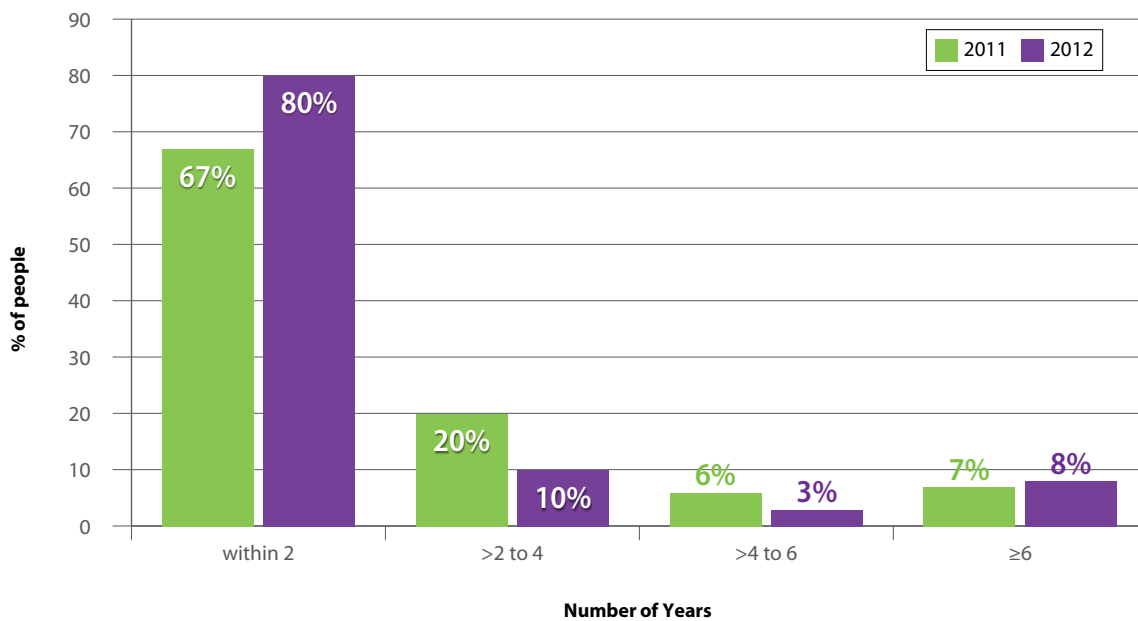
Of the 888 patients who provided this information, it was found that 68% (604) were in regular paid employment.

Table 7 History of MS within Family

MS Family History	2010		2011		2012		Total	
	Number	%	Number	%	Number	%	Number	%
History of MS in family	44	10.5%	36	9.3%	29	6.7%	109	8.8%
No History of MS in family	296	70.9%	264	68.0%	211	49.0%	771	62.3%
Unknown / not disclosed	78	18.7%	88	22.7%	191	44.3%	357	28.9%
Total	418	100%	388	100%	431	100%	1237	100%

Of the 880 patients who provided this information, it was found that 88% (771) had no history of MS in their family.

Figure 10 Percentage of people with a new diagnosis of MS in Scotland in 2011 and 2012, by number of years from first symptoms of MS to confirmed diagnosis



In an attempt to improve the registration of newly diagnosed people with MS the decision was taken by the MS Register Steering Group to reduce the data set. Since October 2011, completion of the first symptoms information has been made optional; this has resulted in an increase in this information being omitted from 179 proforma (46%) in 2011 to 272 (63%) in 2012. This graph does not include missing information or unknown dates of first reported symptoms.

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. 80% of people diagnosed with MS in 2012 were formally diagnosed within 2 years from the first sign of symptoms.

Section 3 Data Linkage

There is a vast amount of information collected by Health Boards in Scotland about hospital admissions. As the register is able to identify people with a new diagnosis of MS, we have been able to link the two sets of information together. The linkage of routinely collected hospital information has allowed the register to reduce information submitted by general neurologists. This has resulted in a simpler registration form.

The method for the study was that all patients on the Scottish MS Register have a definite diagnosis as defined by the McDonald and Poser Criteria. The diagnosis is made by a consultant neurologist who starts the registration form. The diagnosis date is the date the patient is informed by a neurologist.

Information was linked from 01.01.10 until 30.09.12 of the Scottish MS Register. Time period was from 1997 until November 2011 from the routinely collected Scottish hospital admissions from the Scottish Morbidity Records (SMR01) system. Both information sources are part of Information Services Division, National Services Scotland. All information is stored in accordance with ISD Project Governance Policy.

Patients entered onto the Scottish MS Register are given a unique number. The information collected on a paper proforma is split into patient identifiable and non patient identifiable information and entered on to separate electronic file within a secure ISD, NSS IT server.

The register provided patient identifiable information (for example CHI is present in all but 2 people) that enabled the linkage process to match the two sets of information. The Scottish MS Register unique number acted as the identifier between the MS Register and the hospital admission (SMR 01) records. The register's unique number allows verification of the information during case-note validation. The linked information did not leave the ISD NSS secure server. Access to these files is restricted to the Clinical Co-ordinator, Analyst and Principle Analyst for MS by an individual username and password.

Results

930 people were reported to the Scottish MS Register between 01.01.10 until 30.11.12.

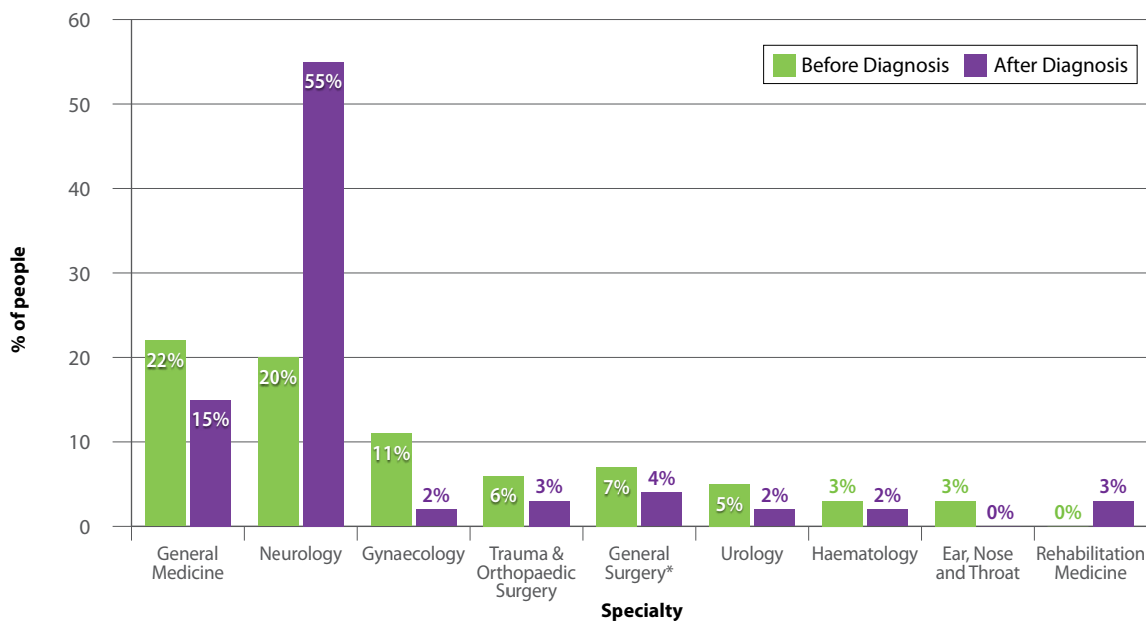
Of the 930, the number of patients from the Scottish MS Register whose data was able to be linked with SMR01 was 798 (86%), with 363 (45%) out of 798 with a diagnosis of MS recorded on SMR01. A possible explanation for the 14% who were not matched or who did not have a diagnosis of MS recorded is that people with MS are not routinely admitted to hospital to make the diagnosis; most people with MS will receive their diagnosis in an out patient setting.

The rest of this section will now talk about the 798 people who were matched with the hospital data. For the 798 people, between 1997 and November 2012, there was a total 3453 admissions to hospital.

Figure 11 How many hospital admissions did people with MS have before and after MS Register date of diagnosis?



Figure 12 Hospital Admission information: What type of specialty were people under the care of, before and after their date of diagnosis?



*excluding vascular.

Further work is underway to link the hospital outpatient information to the register information to report next year on Clinical Standards—October 2009, Neurological Health Services, Standard 16.1a: patients with Multiple Sclerosis have access to a review by an MS specialist service at least every 12 months.

