

Scottish Multiple Sclerosis Register National Report 2014

Data relating to 01.01.2010–31.12.2013



Scottish
MS Register

Scottish MS Register Contact List

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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/)

<http://www.mssociety.org.uk/>

[MS Society—What is MS?](http://www.mssociety.org.uk/what-is-ms/information-about-ms/about-ms)

<http://www.mssociety.org.uk/what-is-ms/information-about-ms/about-ms>

[MS Trust—What is MS?](http://www.mstrust.org.uk/information/what-is-ms/)

<http://www.mstrust.org.uk/information/what-is-ms/>

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

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

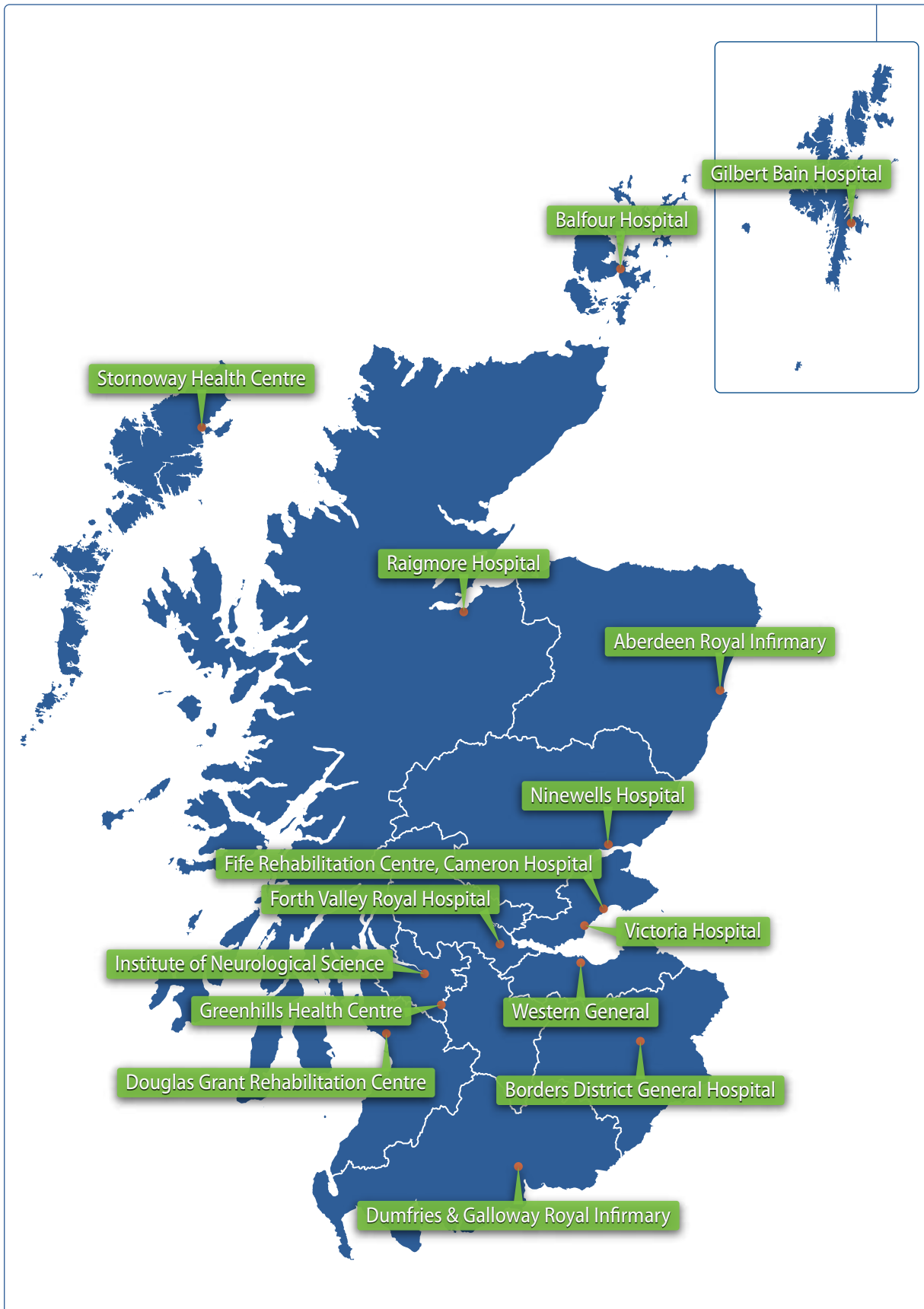
[MS Society—UK MS Register Portal](http://www.ukmsregister.org/Portal/Home)

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

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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 (SMSR) 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 Board	Hospital / Health Centre	Lead Consultant
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Paul Mattison
Borders	Borders District General Hospital	David Simpson
Dumfries & Galloway	Dumfries & Galloway 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	***
Lanarkshire	Greenhills Health Centre	James Overell
Lothian	Western General Hospital	Belinda Weller (Chair)
Orkney	* Balfour Hospital	*
Shetland	Gilbert Bain Hospital	James Unsworth
Tayside	Ninewells Hospital Perth Royal Infirmary	Johnathan O’Riordan Johnathan O’Riordan
Western Isles	** Stornoway Health Centre	Razvi Saif

- * for information, please contact Moira Flett, MS Nurse Specialist
- ** diagnosis made by a General Neurologist from Institute of Neurological Science, Glasgow
- *** for information, please contact Anne Stewart, MS Nurse Specialist

NHS Board	Hospital / Health Centre	Register Co-ordinator
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Jacque Downs
Borders	Borders District General Hospital	Lorna Rogerson
Dumfries & Galloway	Dumfries & Galloway 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
Highlands	Raigmore Hospital	Anne Stewart
Lanarkshire	Greenhill 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 continually improve the information collected.

Introduction

The Scottish MS Register has been established to collect information about people with a new diagnosis of multiple sclerosis with neurologists and MS clinical teams providing the data on which this report is based.

As the Register has achieved the collection of verifiable data comprising the incidence of MS in Scotland during the four years from the beginning 2010 and is now progressing through its fifth year, it is worth reflecting upon the significance of this audit to patients, clinicians, and NHS Boards. By the end of the forthcoming year, it is likely that the Register will contain information on circa 2,200 new confirmed diagnoses of MS in Scotland and this information provides epidemiological data that will be increasingly utilised to focus upon health improvement. The Register also facilitates and stimulates research to assist our understanding of the reasons for the very high incidence and prevalence of the condition within the Scottish population.

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 NHS 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 continue to be made. It is envisaged 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 should 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 endeavor will provide information which will be used to improve the quality of life of people with MS.

Dr. George Mowat-Brown
Chair MS Patient Representative 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 and clinical input to the Register team, and to optimise the use of the data.

The organisational structure of the Scottish MS Register is:

- **Dr Belinda Weller**—Chair of the Steering Group
- **Anita Pritchard**—Clinical Co-ordinator until 31st June 2014
- **Hazel Dodds** —Senior Nurse (Clinical Co-ordinator)
- **Amanda Gilmour**—Information Analyst

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 cord. 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. These assumptions, however, were based upon small studies of discrete parts of the nation and it was only with the initiative of the then Director of the MS Society Scotland, Mark Hazelwood, that the Scottish MS Register was established and this national collection of data occurred. We are now 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 recognised and supported the need for robust national datasets to enable both individuals and organisations 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.

The necessary improvement of the service provision has been identified and reported upon in previous reports especially the procedural delays within the clinical reporting system where MS Nurse Specialists have highlighted to clinical staff where these delays were occurring and to stress to the administrative systems that the earlier they receive a referral, the sooner the support from the MS team can be initiated. This improvement continues with 57% of newly diagnosed patients being contacted within two weeks of their diagnosis — this not only surpasses the Health Improvement Scotland (HIS) standard, but is an improvement on the previous figure of only 46%. Once the MS Nurse Specialist receives the referral, 86% of patients are then contacted within two weeks. Administrative procedural delays in the reporting system are still evident in a number of cases, however, with the referral to the MS Nurse taking longer than six weeks for 11% of patients.

The Register is now progressing from principally recognising 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 being 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 aim of the Scottish MS Register is to improve healthcare for people living with MS in Scotland. Establishing the incidence of MS and interpreting the implications of its demography allows us to facilitate service evaluation and drive improvement. The Register relies on clinicians and MS Nurse Specialists to submit data on all people with a confirmed diagnosis of MS via a standard proforma.

The SMSR Steering Group directs the activities of the Scottish MS Register and has recently focused on:

- Investigating areas of under reporting. There continues to be concern amongst the SMSR Steering Group that there are areas of under reporting within various NHS Boards. It is planned to review the SMSR data collection process and completeness of the SMSR data in the coming year.
- In an attempt to ensure data completeness the MS Register has linked with Scottish Morbidity records (SMR) (see page 20 and 21). However, the Register is also exploring the potential to compare its database with Practice Team Information (PTI) held within ISD. It is hoped that this additional linkage work will further improve the quality/ completeness of the Register data by identifying people who fit the Register's criteria and are not on the Register.
- Establishment of routine quality feedback reports. This report monitors the proportion of patients who are contacted by an MS Nurse within 2 weeks of diagnosis, meeting HIS standard 15.2. Reports are produced every 3 months and monitor each stage in the referral process from time of diagnosis to contact by the MS Nurse at national, local and individual level. People with MS whose care does not meet HIS standard 15.2 are identified for local review.

Future Plans

The Scottish MS Register has identified that there is a need to explore and develop, either through audit or research, areas to improve patient management and services. Forthcoming Steering Group meetings will assess/ discuss the following and the central Register team will support the ongoing development of the MS Register:

- Explore the utilisation of Disease Modifying Treatments (DMTs);
- Review of HIS Neurological Standards relevant to MS;
- Improve routine reporting of performance against the HIS Neurological Standards;
- Utilisation of timely data collection and reporting to drive improvements in the management of MS patients across Scotland;
- Review and follow up of performance against standards with individual NHS Boards;
- Review of current dataset and inclusion criteria;
- Development of a research portfolio; and
- Auditing relapse management pathways.

The MS Register has a Patients Reference Group which comprises people with MS and their carers from across 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 effected by MS, as well as the professionals who are involved in providing advice, support, treatment and care.

Hazel Dodds

Senior Nurse (Clinical Co-ordinator)

Summary & Key points

- On the 31st March 2014, 1698 people had been reported to the MS Register; 421 with a date of diagnosis in 2010, 389 in 2011, 437 in 2012, and 451 in 2013.
- Over the four year time period 20 people (1%) declined contact with an MS Nurse Specialist.
- In 2013, more than twice as many women (325, 72%) as men (126, 28%) were diagnosed with MS.
- 57% of people newly diagnosed with MS in 2013 had contact with an MS Nurse Specialist within two weeks of diagnosis. This is an 11% improvement on 2012.
- 7% of people were supported by an MS Nurse Specialist prior to being given a confirmed diagnosis of MS in 2013.
- In 2013, nationally the time response within two weeks was very effective (86%) once the MS Nurse Specialist received patients referral.
- Delays in referral to MS Nurse and delays in MS Nurse receiving referral continue to be problematic.
- The majority (83%) of people diagnosed in 2013 were referred to an MS Nurse Specialist within 2 weeks of receiving a confirmed diagnosis; however 11% of people waited over 6 weeks before being referred. This is a 4% improvement on 2012.
- The majority (84%) of referrals to an MS Nurse Specialist in 2013 were received within 2 weeks; however 13% of referrals took between 2 and 4 weeks before being received by an MS Nurse. This is a 3% improvement on 2012.
- Quality feedback reports, targeting individual steps in the referral process, are sent quarterly to MS clinical leads and MS Nurse Specialists in order to identify delays and target solutions at a local level.

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’.

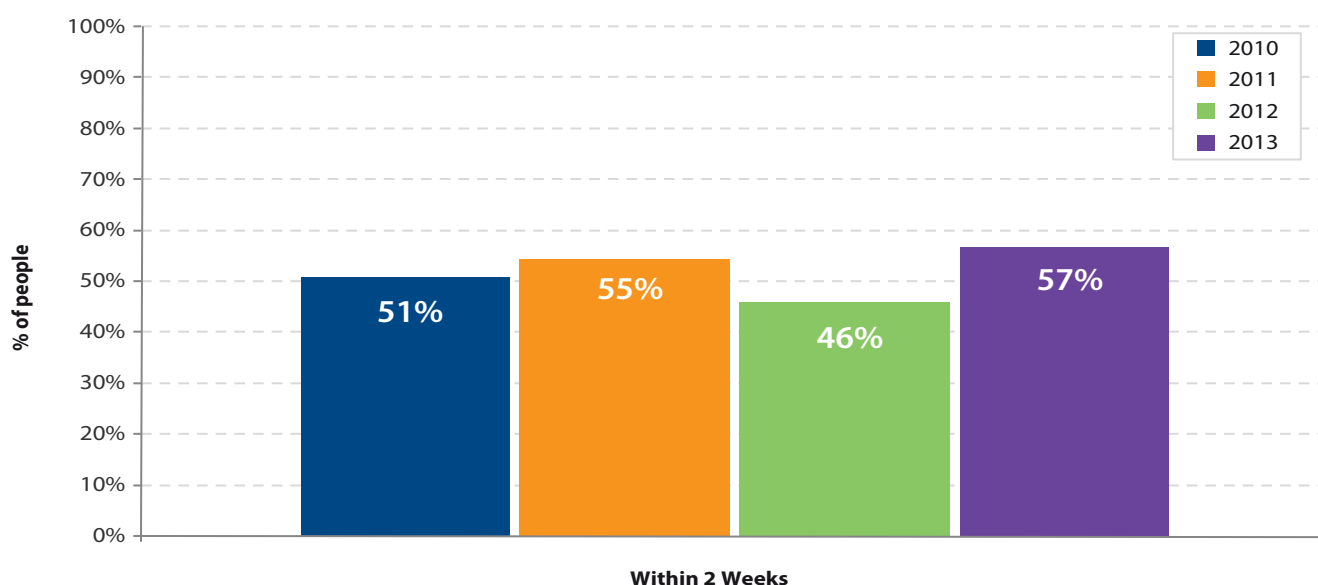
Figures 1 and 2 provide details of the length of time it took for people diagnosed with MS to be referred and to have first contact with a MS Nurse. (Whole Journey Time).

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.

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?

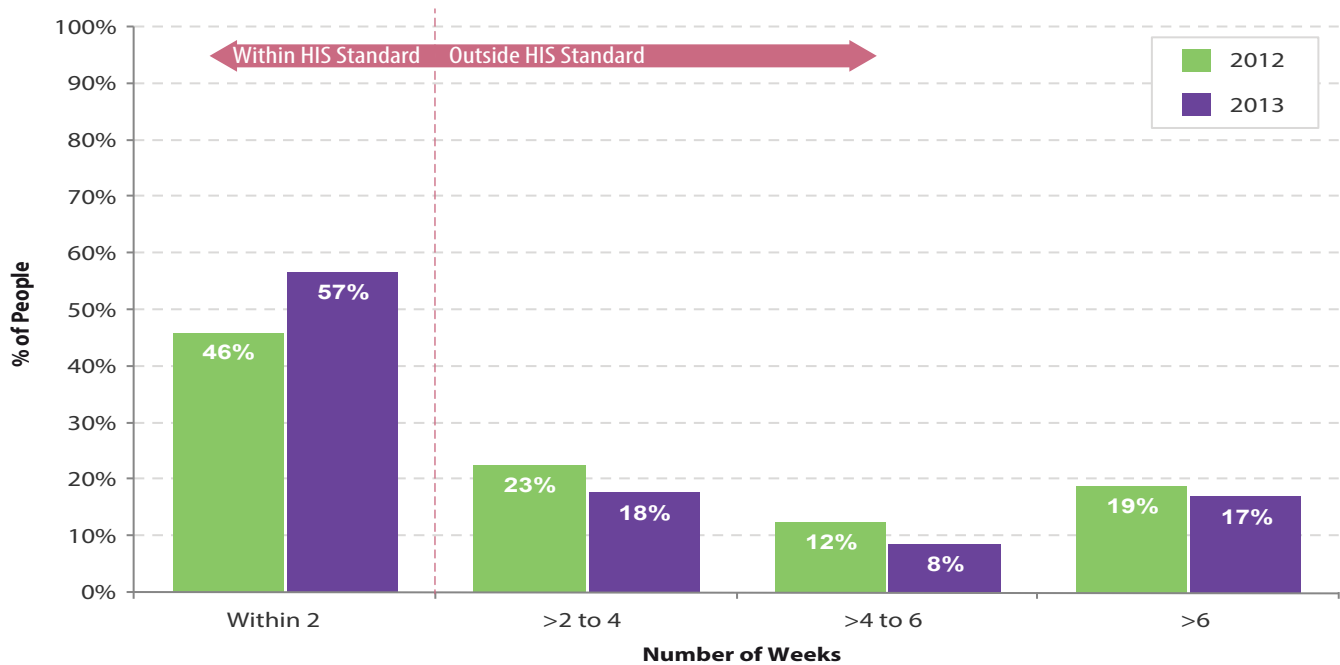
Figure 1 Percentage of people with a new diagnosis of MS in Scotland contacted by MS Nurse within two weeks of confirmed diagnosis, meeting HIS standard 15.2 by year



Percentages above are calculated using cases where contact with an MS Nurse Specialist was not declined and a date of diagnosis and date of 1st contact was recorded. Cases for which contact was declined (Nbr = 20) and cases where dates were incomplete/unavailable (Nbr = 19) have been excluded.

With the exception of 2012, there has been a general increase in the percentage of people meeting HIS standard 15.2 across the four year time period. In 2013, the percentage of people meeting the HIS standard reached its highest of 57%. This was an 11% improvement on 2012 where it reached its lowest of 46%.

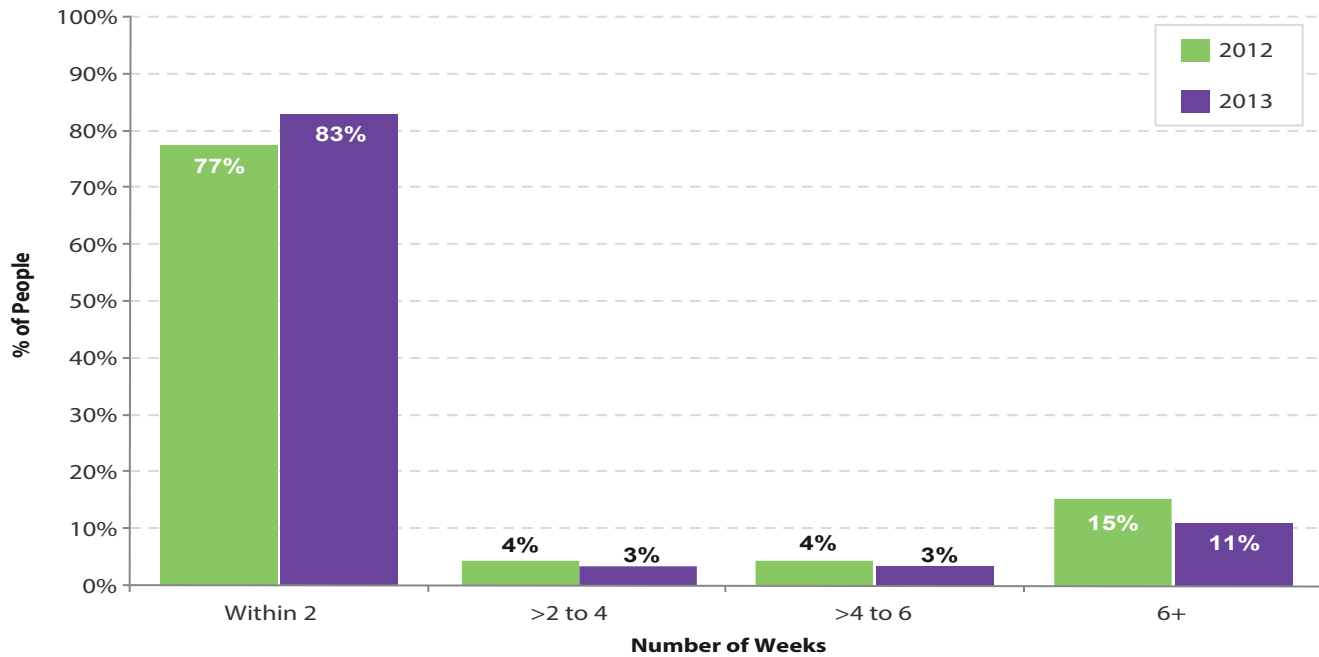
Figure 2 Percentage of people with a new diagnosis of MS in Scotland in 2012 and 2013, by number of weeks from confirmed diagnosis to first contact with MS Nurse



Percentages above are calculated using cases where contact with an MS Nurse Specialist was not declined and a date of diagnosis and date of 1st contact was recorded. Cases for which contact was declined (Nbr = 6) and cases where dates were incomplete/unavailable (Nbr = 11) have been excluded.

In 2013, 7% of people were supported by an MS Nurse Specialist prior to being given their diagnosis. Figure 2 illustrates a noticeable improvement in the percentage of people being contacted within 2 weeks of diagnosis in 2013 (57%) compared to 2012 (46%). However the percentage of people waiting over 6 weeks to be contacted by an MS Nurse Specialist after receiving a confirmed diagnosis still remains relatively high (17%).

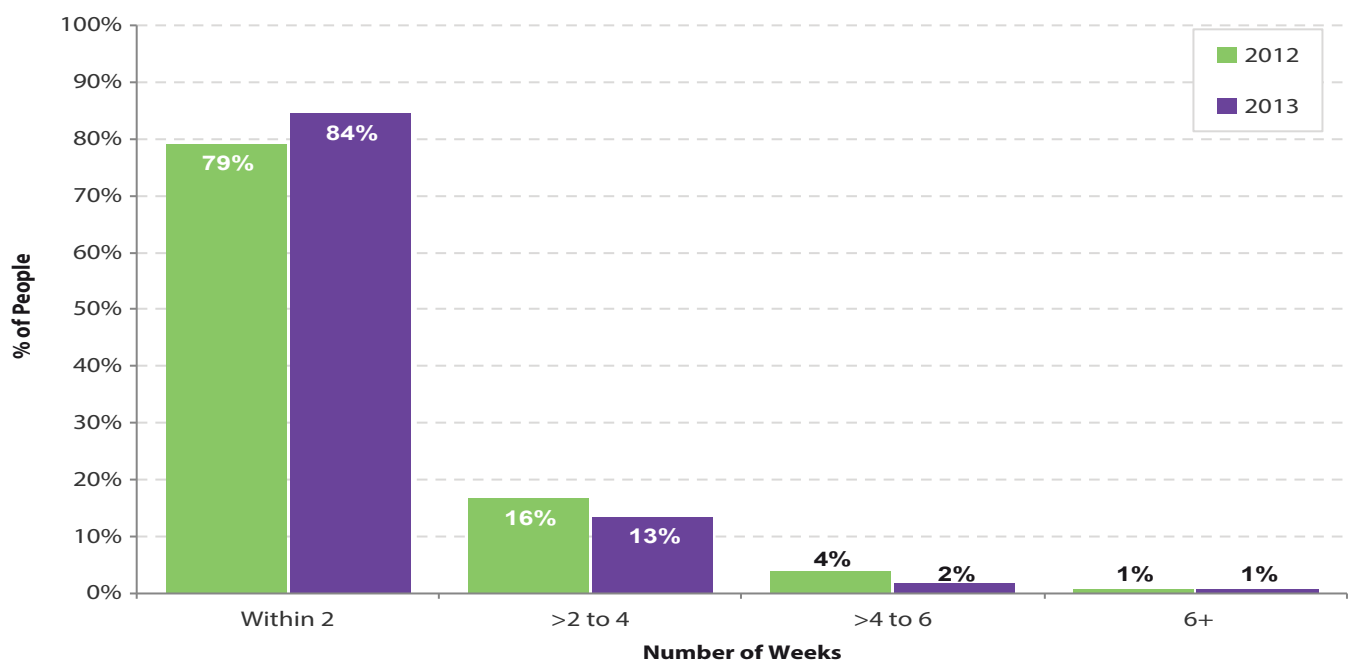
Figure 3 Percentage of people with a new diagnosis of MS in Scotland in 2012 and 2013, by number of weeks from confirmed diagnosis to person being referred to MS Nurse



Percentages above are calculated using cases where contact with an MS Nurse Specialist was not declined and a date of diagnosis and date of referral was recorded. Cases for which contact was declined (Nbr = 6) and cases where dates were incomplete/unavailable (Nbr = 10) have been excluded.

The majority (83%) of people who received a confirmed diagnosis of MS in 2013 were referred to an MS Nurse Specialist within two weeks of being diagnosed. This is a 6% improvement on 2012. 11% of people were referred to an MS Nurse Specialist more than 6 weeks after receiving a diagnosis. This is a 4% improvement on 2012; however still remains relatively high

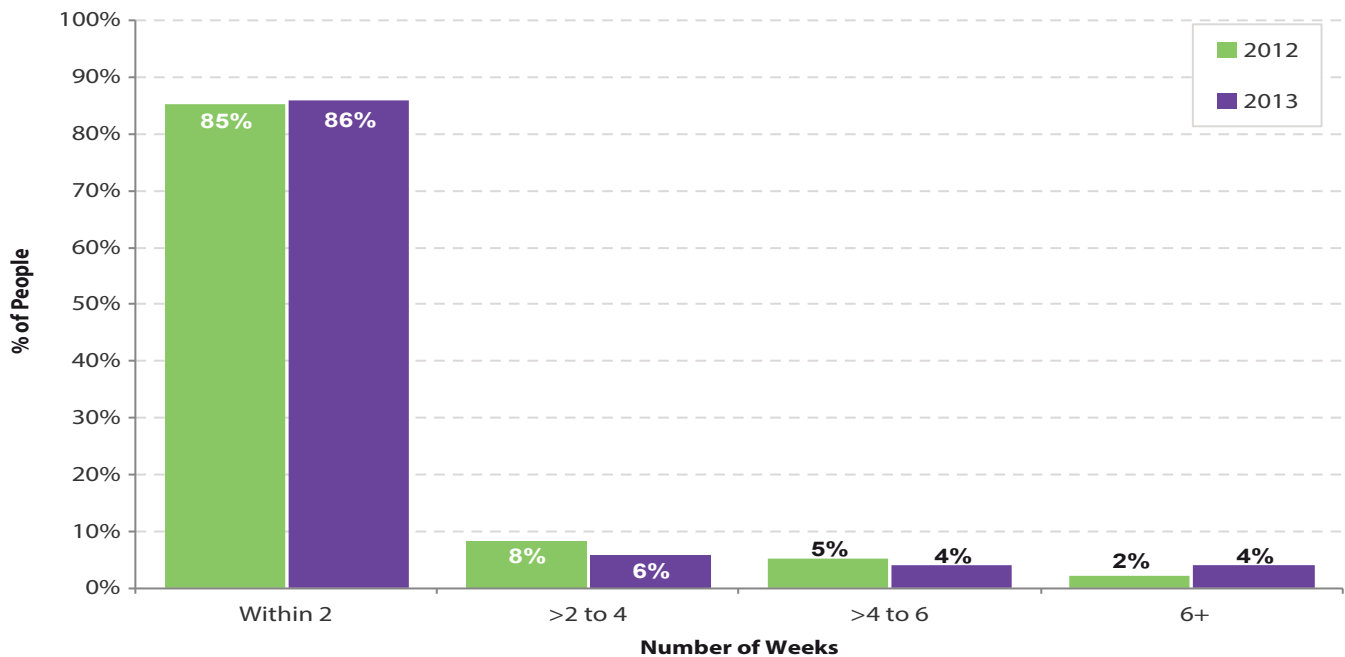
Figure 4 Percentage of people with a new diagnosis of MS in Scotland in 2012 and 2013, by number of weeks from referral to MS Nurse receiving referral



Percentages above are calculated using cases where contact with an MS Nurse Specialist was not declined and a date of referral and date of referral received was recorded. Cases for which contact was declined (Nbr = 6) and cases where dates were incomplete/unavailable (Nbr = 21) have been excluded.

The majority (84%) of referrals sent to an MS Nurse Specialist in 2013 were received within two weeks. This is a 5% improvement on 2012. 13% of referrals took between 2-4 weeks to reach the MS Nurse Specialist. This is a 3% improvement on 2012; however figure still remains relatively high.

Figure 5 Percentage of people with a new diagnosis of MS in Scotland in 2012 and 2013, by number of weeks from MS Nurse receiving referral to person being contacted by MS Nurse



Percentages above are calculated using cases where contact with an MS Nurse Specialist was not declined and a date of referral received and date of 1st contact was recorded. Cases for which contact was declined (Nbr = 6) and cases where dates were incomplete/unavailable (Nbr = 20) have been excluded.

Despite only 57% of people meeting HIS standard 15.2 in 2013 (Fig.2), the time response within two weeks, as with previous years, remains very effective (86%) 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 delays in MS Nurse receiving referral may be accountable for only 57% of people meeting the HIS standard. MS team should examine delays in the referral process locally to target solutions or resources.

Section 2 Demographics

A total of 1698 people were diagnosed and reported to the Scottish MS Register from 1st Jan 2010 to the 31st Dec 2013. Table 1 shows that the number of people being reported to the MS Register is improving year on year, however, there remains some concern that there are 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, 2012 and 2013 reported by NHS Board

NHS Board	Year of Diagnosis			
	2010	2011	2012	2013
Ayrshire & Arran	16	27	34	35
Borders	8*	7*	7*	5*
Dumfries & Galloway	12	16	15	24
Fife	29	26	33	32
Forth Valley	17	23	25	26
Grampian	54	49	59	64
Greater Glasgow	98	91	88	87
Highland	27	19	26	34
Lanarkshire	46	22	41	25
Lothian	59	54	48	69
Orkney	5	5	1*	0*
Shetland	4	6	1*	1*
Tayside	41	42	56	46
Western Isles	5	2*	3*	3*
Total	421	389	437	451

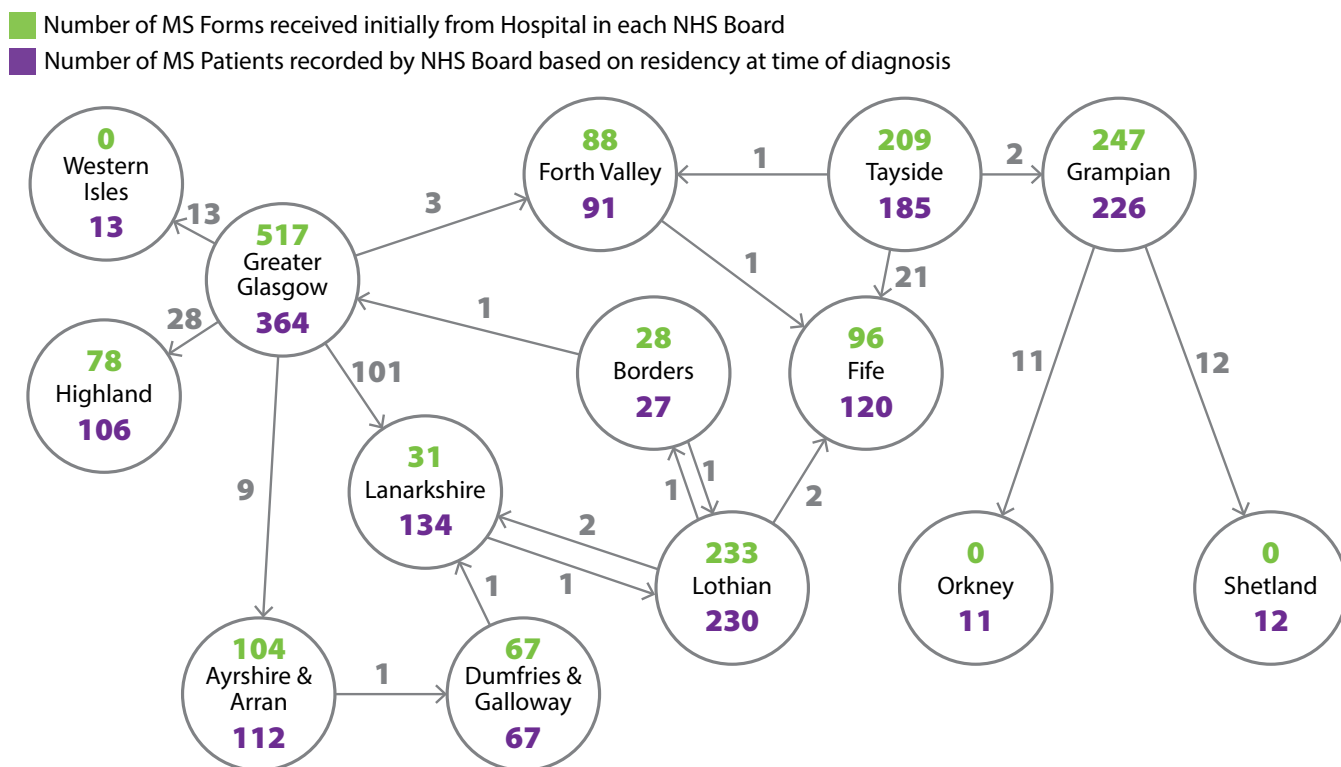
* Data are incomplete due to collection problems. 2013 annual publication recorded 17 cases reported by Ayrshire & Arran in 2010. Through our validation process this year, it was identified that one of these cases was a duplicate case. This has consequently been removed leaving 16 cases in total.

Table 2: Number of people with a new diagnosis of MS in Scotland in 2010, 2011, 2012 and 2013 reported by hospital from which Register receives form

Hospital	Year of Diagnosis			
	2010	2011	2012	2013
Aberdeen Royal Infirmary	63	60	60*	64*
Ayrshire Central, Irvine	12	27	33	32
Borders District General Hospital	8*	8*	8*	4*
Cameron Hospital, Fife	21	20	26	29
Dumfries & Galloway Royal Infirmary	12	15	16	24
Forth Valley Royal Hospital	17	23	23	25
Greenhills Health Centre, East Kilbride	0	3	18	10
Institute of Neurological Science, Glasgow	160	119	122	116
Ninewells Hospital, Dundee & Perth Royal Infirmary	48	47	64	50
Raigmore Hospital, Inverness	19	12	19	28
Western General Hospital	61	55	48	69
Total	421	389	437	451

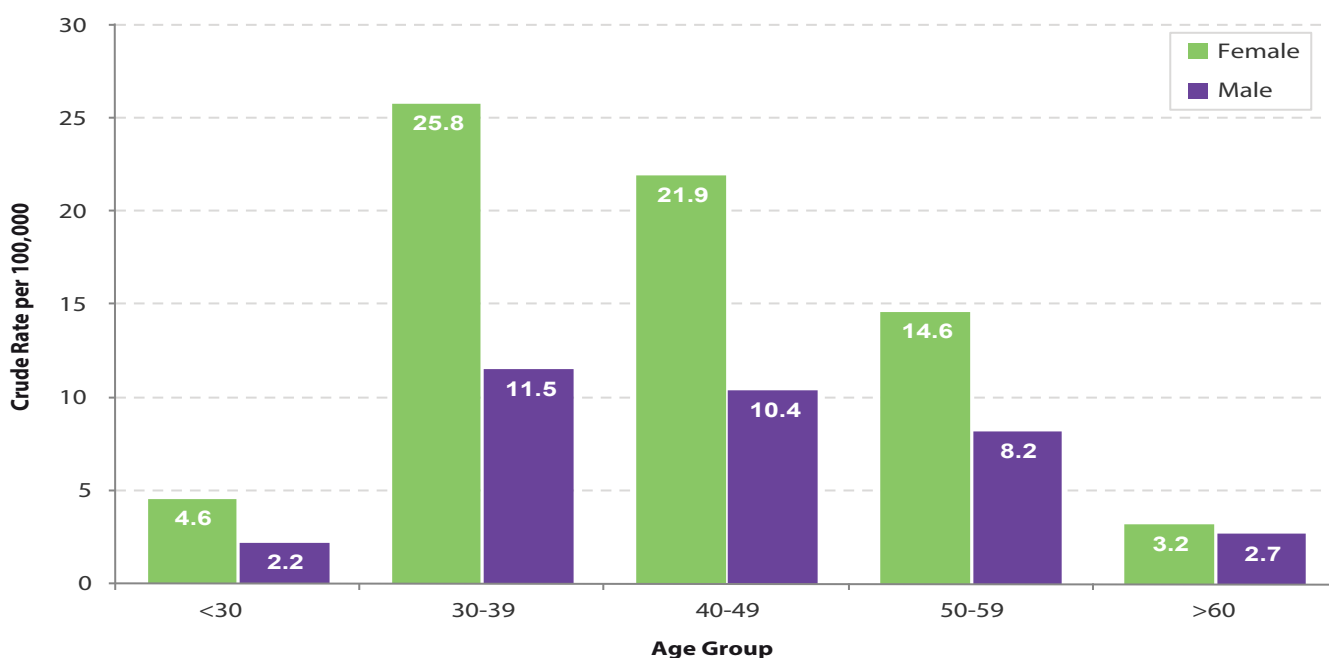
* Data are incomplete due to collection problems. 2013 annual publication recorded 13 cases reported by Ayrshire Central, Irvine in 2010. Through our validation process this year, it was identified that one of these cases was a duplicate case. This has consequently been removed leaving 12 cases in total.

Figure 6 Number of patients with a new diagnosis of MS from 01.01.2010 to 31.12.2013 (NHS Board diagnosed under vs. NHS Board of residency at time of diagnosis)



The majority of people being diagnosed with MS will be given the diagnosis from a General Neurologist from Greater Glasgow & Clyde NHS Board. On the 31st of March 2014, a total of 517 MS incidence forms were collected from the Institute of Neurological Science (INS), under NHS GG&C. However, 30% of people diagnosed reside in other NHS Boards. These include Western Isles, part of Highlands, Forth Valley, Lanarkshire and Ayrshire & Arran.

Figure 7 Crude Rate per 100,000 of people with a new diagnosis of MS in Scotland in 2012, by gender and age at time of diagnosis



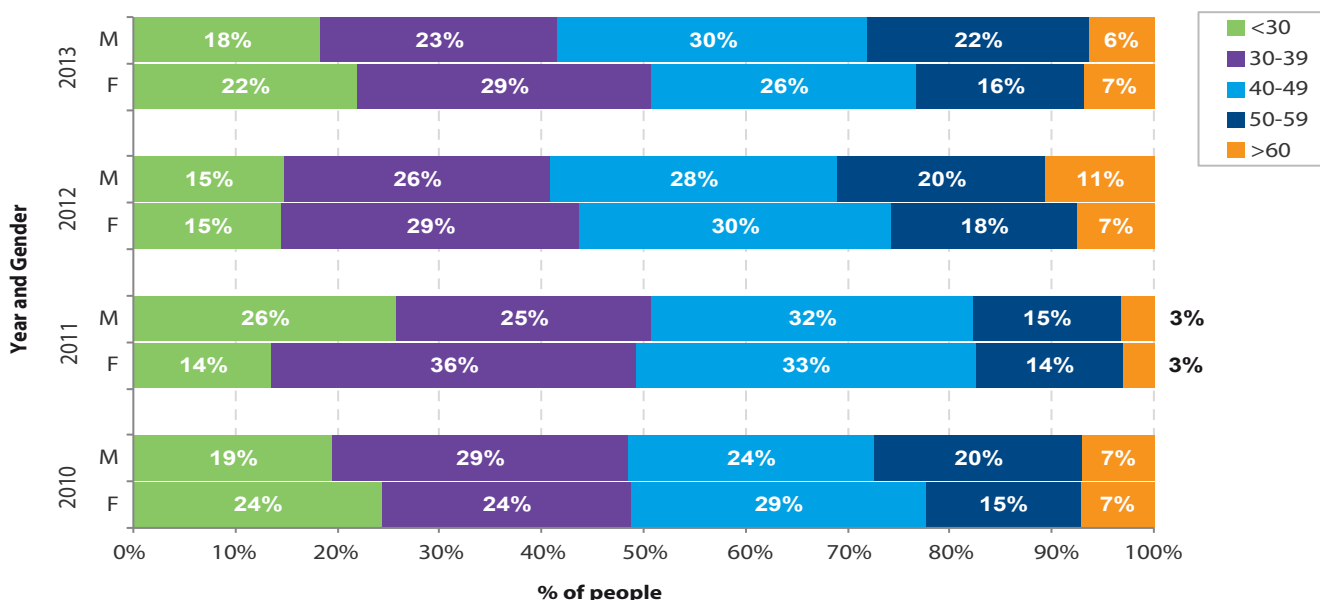
On 31st March 2014, 1698 people were Registered, 421 with a date of diagnosis in 2010, 389 in 2011, 437 in 2012 and 451 in 2013. More than twice as many women (295, 68%) as men (142, 32%) were diagnosed with MS in 2012.

Table 3 Crude rate per 100,000 of people with a new diagnosis of MS in Scotland in 2012, by gender and age at time of diagnosis

Age Group	Male	Population	Crude Rate	Female	Population	Crude Rate
<30	21	954,783	2.2	43	935,698	4.6
30-39	37	321,439	11.5	86	333,531	25.8
40-49	40	385,726	10.4	90	410,039	21.9
50-59	29	354,439	8.2	54	369,556	14.6
>60	15	560,753	2.7	22	687,636	3.2
Total	142	2,577,140	5.5	295	2,736,460	10.8

Crude Rate is calculated as the number of patients per 100,000 within the population of each age group.

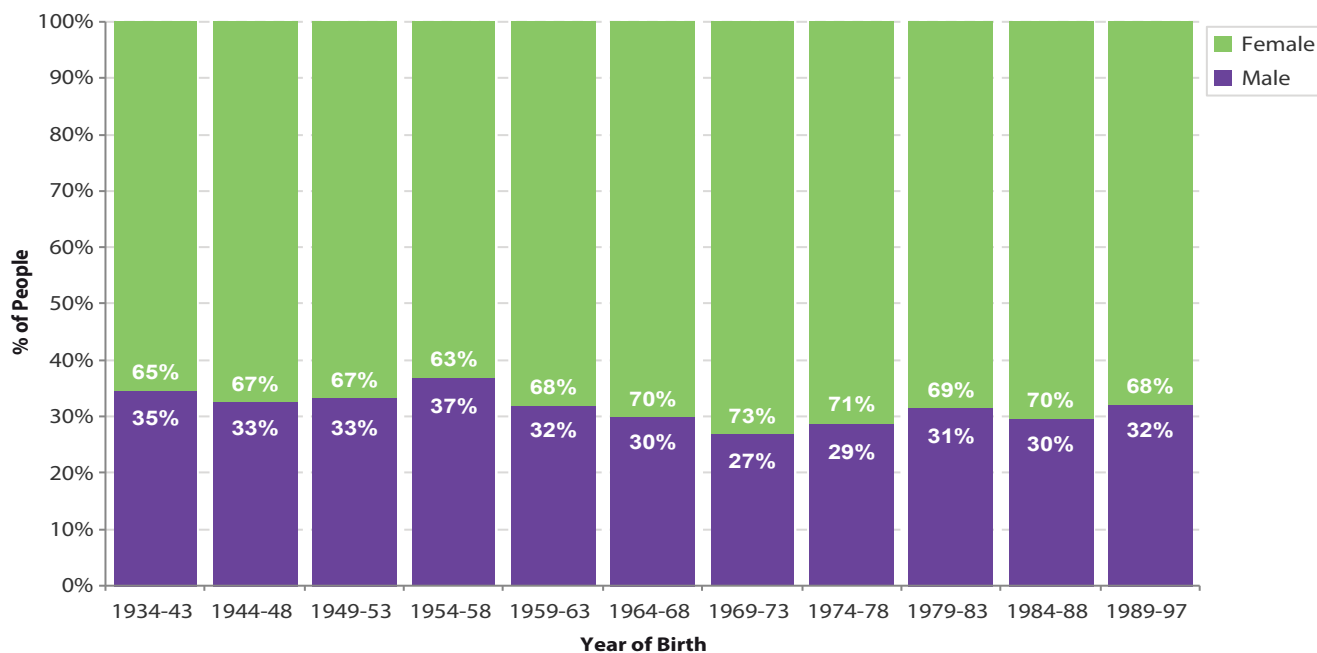
Figure 8 Percentage of people with a new diagnosis of MS in Scotland by gender, year and age time of diagnosis



Percentages above are calculated using cases with a recorded date of diagnosis, gender and date of birth. Cases where any of this information was incomplete/unavailable have been excluded (Nbr = 6).

Despite a growing number of people being referred to the Register there are concerns that certain age groups are not accurately represented. The majority (53-69%) of both males and females were diagnosed between 30-49 years of age for all 4 years. This contradicts Rothwell & Charlton (1998) who found that MS diagnosis is most common in the 20-40 year age range.

Figure 9 Percentage of people newly diagnosed with MS in Scotland between 01.01.2010 until 31.12.2013, by gender and year of birth



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 to 2013. 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; Ayr Hospital; Raigmore Hospital; Ninewells Hospital; Falkirk & District Royal Infirmary; Forth Valley Royal Hospital; Dumfries & Galloway Royal Infirmary.

Table 4 Country of Birth

Country of Birth	2010		2011		2012		2013		Total	
	Number	%	Number	%	Number	%	Number	%	Number	%
Scotland	181	43.0%	148	38.0%	127	29.1%	143	31.7%	599	35.3%
Other UK	16	3.8%	19	4.9%	12	2.7%	6	1.3%	53	3.1%
Other	11	2.6%	12	3.1%	26	5.9%	11	2.4%	60	3.6%
Unknown / not disclosed	213	50.6%	210	54.0%	272	62.2%	291	64.6%	986	58.0%
Total	421	100%	389	100%	437	100%	451	100%	1698	100%

Table 4 illustrates that of the 712 patients who provided this information, it was found that 84% (599) stated that Scotland was their country of birth.

Table 5 Domestic Status

Domestic Status	2010		2011		2012		2013		Total	
	Number	%	Number	%	Number	%	Number	%	Number	%
Living alone	54	12.8%	53	13.6%	42	9.6%	46	10.2%	195	11.5%
Living with spouse / partner	190	45.1%	145	37.3%	155	35.5%	100	22.2%	590	34.7%
Living with family	115	27.3%	77	19.8%	26	5.9%	43	9.5%	261	15.4%
Other	2	0.5%	0	0.0%	7	1.6%	4	0.9%	13	0.8%
Unknown / not disclosed	60	14.3%	114	29.3%	207	47.4%	258	57.2%	639	37.6%
Total	421	100%	389	100%	437	100%	451	100%	1698	100%

Table 5 illustrates that of the 1059 patients who provided this information, it was found that 56% (590) currently resided with their partner/spouse.

Table 6 Employment Status

Employment Status	2010		2011		2012		2013		Total	
	Number	%	Number	%	Number	%	Number	%	Number	%
Regular paid employment	227	53.9%	213	54.8%	165	37.7%	139	30.8%	744	43.8%
Self employed	19	4.5%	8	2.1%	0	0.0%	4	0.9%	31	1.8%
Looking after home/family	23	5.5%	11	2.8%	6	1.4%	3	0.7%	43	2.5%
Unemployed	23	5.5%	34	8.7%	33	7.6%	27	6.0%	117	6.9%
In formal education	21	5.0%	8	2.1%	7	1.6%	7	1.6%	43	2.5%
Retired	17	4.0%	6	1.5%	17	3.9%	14	3.1%	54	3.2%
Sick/disabled (permanent or temporary)	28	6.6%	17	4.4%	5	1.1%	2	0.4%	52	3.1%
Other	2	0.5%	2	0.5%	2	0.5%	0	0.0%	6	0.4%
Unknown / not disclosed	61	14.5%	90	23.1%	202	46.2%	255	56.5%	608	35.8%
Total	421	100%	389	100%	437	100%	451	100%	1698	100%

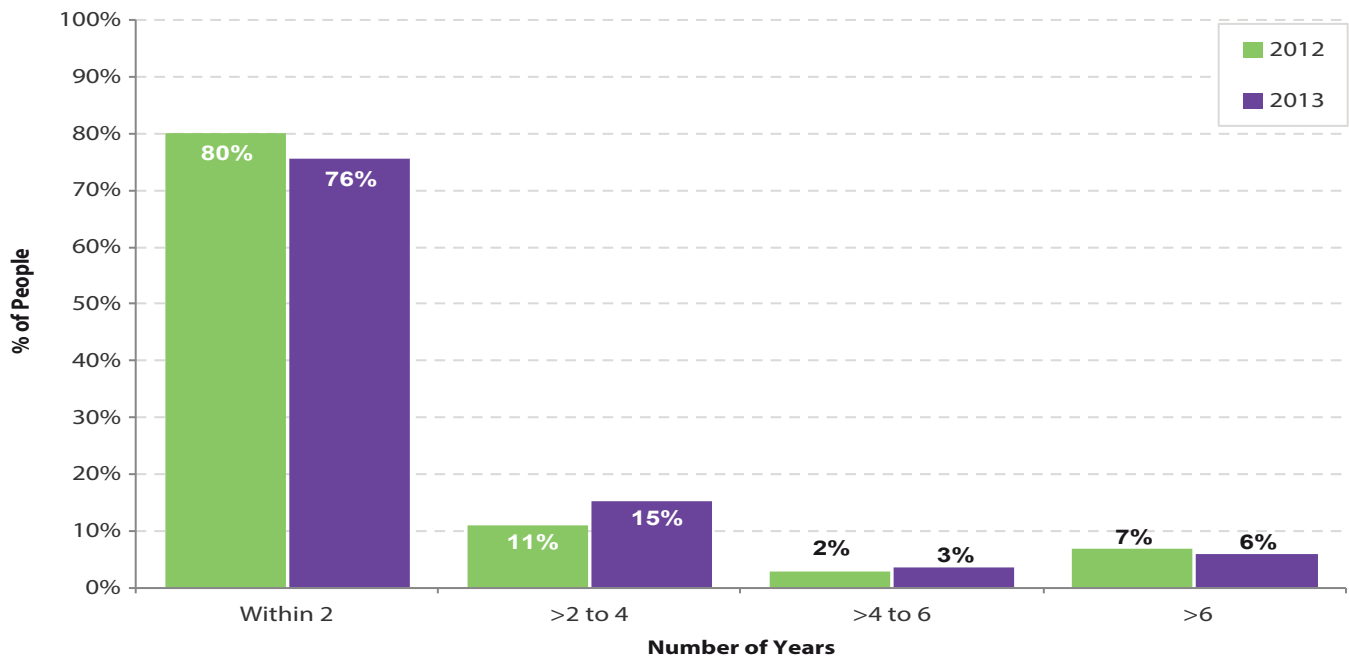
Table 6 illustrates that of the 1090 patients who provided this information, it was found that 68% (744) were in regular paid employment.

Table 7 History of MS within Family

MS Family History	2010		2011		2012		2013		Total	
	Number	%	Number	%	Number	%	Number	%	Number	%
No	297	70.5%	264	67.9%	214	49.0%	180	39.9%	955	56.3%
Yes	44	10.5%	36	9.2%	29	6.6%	26	5.8%	135	7.9%
Unknown / not disclosed	80	19.0%	89	22.9%	194	44.4%	245	54.3%	608	35.8%
Total	421	100%	389	100%	437	100%	451	100%	1698	100%

Table 7 illustrates that of the 1090 patients who provided this information, it was found that 88% (955) had no history of MS in their family.

Figure 10 Percentage of people with a new diagnosis of MS in Scotland in 2012 and 2013, by number of years from first symptoms of MS to confirmed diagnosis



Percentages above are calculated using cases with a recorded date of first symptoms, and date of diagnosis. Cases where any of this information was incomplete/unavailable have been excluded (Nbr = 563)

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 of this information being omitted from 168 proforma (43%) in 2011 to 307 (68%) in 2013.

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 confirmed diagnosis. 76% of people diagnosed with MS in 2013 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 NHS Boards in Scotland regarding 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 data 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 01.01.2010 until 30.06.2014 of the Scottish MS Register and data from 1997 till July 2014 from the routinely collected Scottish hospital admissions from the Scottish Morbidity Records (SMR01) system. Both data sets 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 identifiable and non identifiable data and entered on to separate electronic files within a secure ISD, NSS IT server.

The Register provided identifiable data (for example CHI is present in all but 5 people) that the linkage was able to utilise and match the two sets of information. The Scottish MS Register unique number acted as the identifier between the MS Register data set and the hospital admission (SMR01) data set. The Register's unique number allowed verification of the data during case-note validation. The linked data did not leave the ISD NSS secure server. Access to these files is restricted to the Clinical Co-ordinator for MS, Analyst and Principal Analyst by an individual username and password.

Results

1805 people were reported to the Scottish MS Register between 01.01.10 until 30.06.2014.

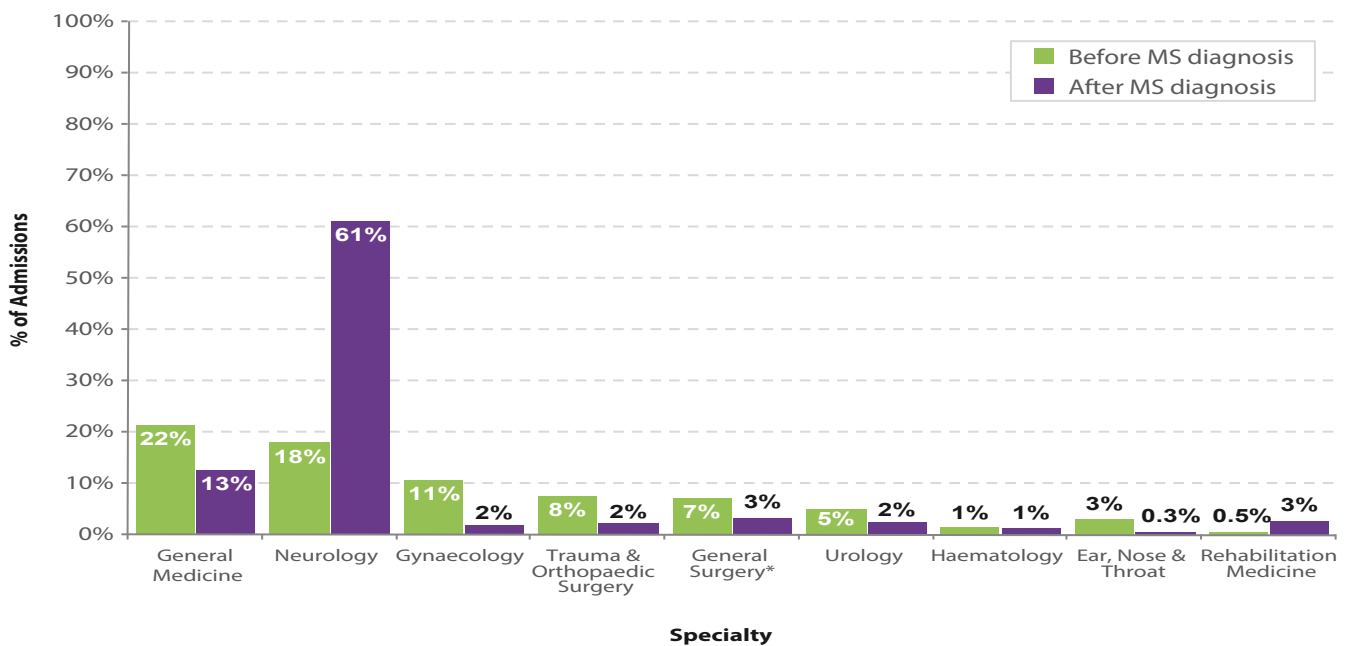
Of the 1805, the number of patients from the Scottish MS Register whose data were able to be linked with SMR01 was 1575 (87%), with 729 (46%) out of 1575 with a diagnosis of MS recorded on SMR01. A possible explanation for the 13% who were not matched or who did not have a diagnosis of MS recorded is that people with MS are not routinely admitted to hospital to make the diagnosis; most people with MS will receive their diagnosis in an outpatient setting.

The rest of this section will now talk about the 1575 people who were matched with the hospital data. For the 1575 people, between 1997 and July 2014, there was a total 8105 admissions to hospital.

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



Figure 12 What percentage of hospital admissions occurred under each specialty before and after MS Register date of diagnosis?



* excluding vascular

Figure 11 provides some insight into the type of interactions people with MS have with healthcare professions within a hospital setting pre and post diagnosis. Most of the 5353 hospital admissions that occurred pre MS diagnosis were either under the care of a general physician (22%), a neurologist (18%) or a gynaecologist (11%). The majority (61%) of the 2752 hospital admission that occurred post diagnosis were under the care of a neurologist; this is a 6% increase from those figures published in 2012 and a 9% increase from those published in 2011.

