

Scottish Multiple Sclerosis Register National Report 2012

Information relating to 01.01.2010–31.12.2011



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

David Readhead

Information Analyst

Healthcare Audits, National Services Scotland

email: davidreadhead@nhs.net

Tel: 0141 282 2314

Stuart Baird

Service Manager

Healthcare Audits, National Services Scotland

email: s.baird@nhs.net

Tel: 0131 275 6333

Useful Websites for further information

[The Scottish MS Register](#)

[ISD Scotland](#)

[Healthcare Improvement Scotland](#)

[MS Society](#)

[MS Society—What is MS?](#)

[MS Trust—What is MS?](#)

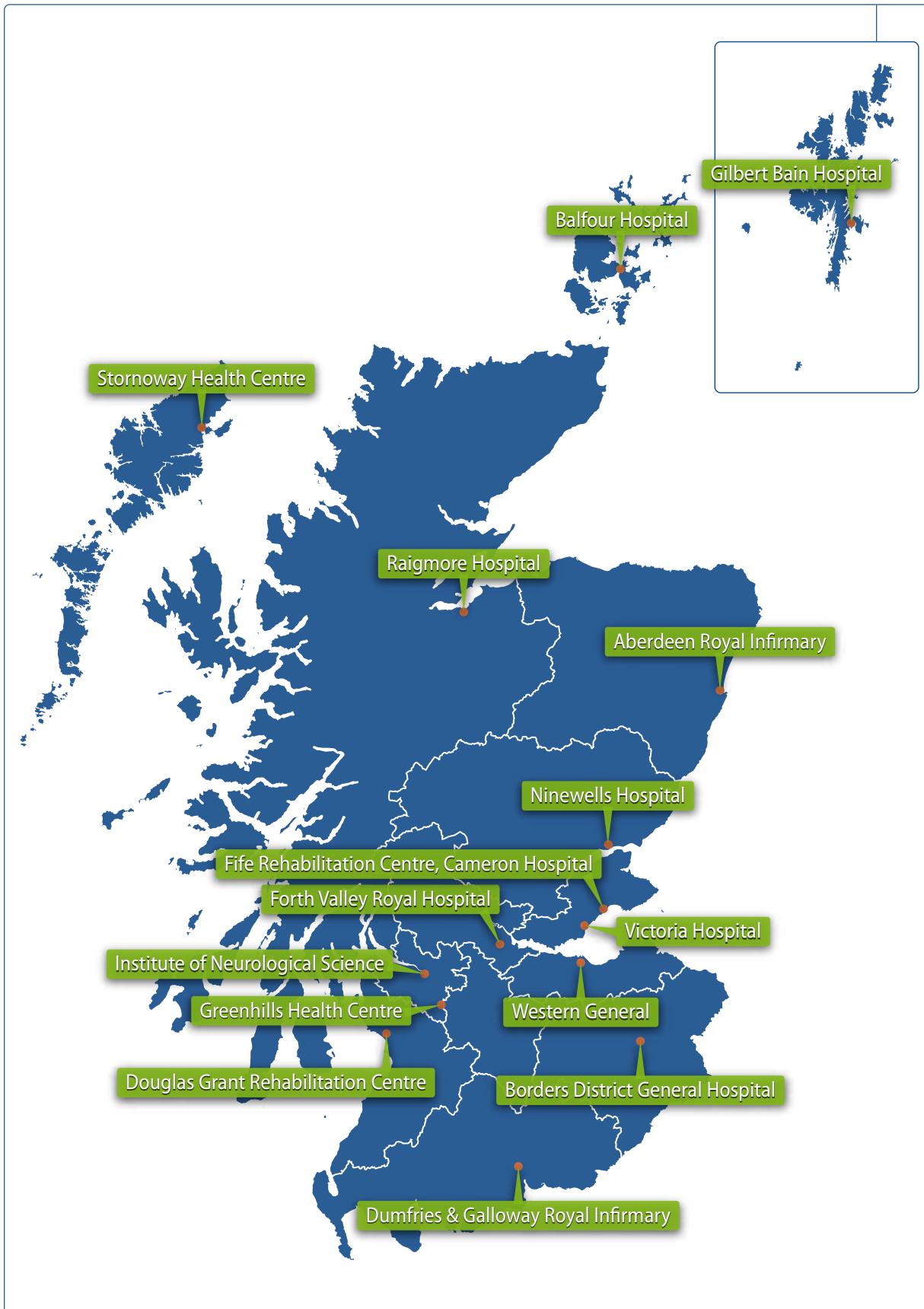
[MS Society—What is the UK Register?](#)

[MS Society—UK MS Register Portal](#)

Contents

Map of Scotland showing all MS service providers by NHS Boards who contribute to the Scottish MS Register	2
Acknowledgements	3
Foreword	4
Introduction	5
Organisational structure of the Scottish MS Register	6
Patient Representative Group of the Scottish MS Register	7
Progress	8
This Report	9
Key points	10
Results	
Section 1 Introduction to NHS HIS Neurological Standards	11
Section 2 Demographics	14
Section 3 Data Linkage	19
Section 4 IT Survey	22

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	Lance Sloan
	Victoria Hospital	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	Johnathan O’Riordan
	Perth Royal Infirmary	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	Jacquie Downs
Borders	Borders District General	Lorna Rogerson
Dumfries & Galloway	Dumfries General Royal Infirmary	Liz Clark
Fife	Cameron Hospital	Debbie McCallion
	Victoria Hospital	Uwe Spelmeyer
Forth Valley	Forth Valley Royal Hospital	Hazel Gaylor
Grampian	Aberdeen Royal Infirmary	Rose Johnston
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	Elizabeth Clarke
Tayside	Ninewells Hospital	Pamela Walker
	Perth Royal Infirmary	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.

Foreword

So much of life with Multiple Sclerosis is a mystery tour - but knowing how many people have the condition, where they live and what kind of care they are receiving should be much more straightforward.

When I presented the BBC documentary, "Scotland's hidden epidemic: the truth about MS", I was shocked to learn that we did not know this. This was especially surprising when you consider Scotland has the highest rate of this neurological condition in the world and must surely be able to provide some of the answers to this puzzling condition.

It was yet more surprising when, as part of my investigation, I discovered that other countries such as Canada have been collating this kind of information for several decades and then using it to help patients.

The Scottish MS Register is therefore a valuable tool in the fight against this condition. This is not about collecting information just for the sake of it, the register should collect the information in order to improve care and highlight where action needs to be taken.

It seems to me to be obvious that if we don't know where people with MS are or what kind of care they are receiving, then how can we ensure we are given the very best opportunity to tackle this condition? The MS Register should hopefully help everyone with MS to get the support we need, when we need it.

Elizabeth Quigley

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 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 management of people with MS.

Belinda Weller

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
- **Stephen Simmons**—Information Analyst until 31st May 2012
- **David Readhead**—Information Analyst from 1st June 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, but for about 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 the 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 MS Register has been established to develop a reliable national database for MS; to develop a culture of improvement that will result in quantifiable improvements in neurological services for patients in Scotland; to report on compliance with national clinical standards to improve their services at a local level. The project has invested time and effort to ensure the data is as complete and accurate as possible. This is possible because of 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.

In October 2009 NHS Healthcare Improvement Scotland (HIS) published Neurological Health Service Standards. Standard 15.2, concerning contact with an MS Nurse specialist after the date of diagnosis, was reported in the 2011 report. This information is now reported to individual MS teams every three months allowing clinicians to investigate delays in their referral process. For example, nationally, in 2011, data from the MS Register showed that 52% of newly-diagnosed people were contacted within 2 weeks of their date of diagnosis, compared to 49% in 2010. Demonstrating how this information can be utilised for service improvement: when the referral process was further investigated it became clear that 81% of people are contacted within 2 weeks from the MS Nurse specialist receiving the referral. This information has identified procedural delays within the reporting system and has allowed MS Nurse specialists to highlight to clinical staff where these delays are 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.

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 register requires a well-designed administrative structure to ensure it is to run successfully. Within [Information Services Division Scotland](#) (ISD) the central data validation system has been created to ensure the accuracy of data and to keep validation checks by clinicians to a minimum. All validations are now run quarterly and are checked prior to clinicians being contacted.

Case-note validation commenced in April 2011; 10% to 20% of case notes in every hospital have been verified against the data submitted and the data definitions. The data item that required most alteration was the date of first symptom. Possible explanation is that more patient information was available at case note review than at the time of the register form completion.

In October 2009 NHS [Healthcare Improvement Scotland](#) (HIS) published the Neurological Health Service Standards. Standard 15.2 regarding contact with MS Nurse specialist after date of diagnosis was reported in the 2011 report. This information is now reported to individual MS teams every three months.

There is a vast amount of information collected by [Health 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.

All Clinical Leads and MS Nurse Specialists within the 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, there may be people who are diagnosed by a visiting General Neurologist and not referred to local services or reported to the register. It is hoped that the three monthly report introduced earlier this year will provide MS teams with information that will highlight areas of concern in the MS service referral process, including under referral of people with a new diagnosis of MS to MS teams.

The **SMR01** database holds records of all inpatient and day case activity in NHS hospitals in Scotland as well as linked data on deaths in Scotland provided by the National Records of Scotland.

The **SMR00** database holds records of outpatient attendances in the NHS in Scotland. It provides information about the speciality providing care (for example in the case of MS, neurology or general medical clinics) but not specific diagnostic information.

This Report

Data on all known patients registered by a Consultant Neurologist with a new definite diagnosis of MS from 1st January 2010 to 31st December 2011 in Scotland were collected using a [standard proforma](#), 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.

Table 1 Number of people with a new diagnosis of MS in Scotland in 2010 and 2011, reported by Hospital from which register receives form

Hospital	Year of Diagnosis	
	2010	2011
Aberdeen Royal Infirmary	63	56
Ayrshire Central, Irvine	13	27
Borders District General*	6	1
Cameron Hospital, Fife	21	18
Dumfries General Royal Infirmary	12	15
Forth Valley Royal Hospital	17	24
Greenhills Health Centre, East Kilbride**	0	3
Institute of Neurological Science, Glasgow	160	120
Ninewells Hospital, Dundee & Perth Royal Infirmary	47	46
Raigmore Hospital, Inverness	18	11
Western General Hospital	59	54
Total	416	375

* Data for Borders District General is incomplete for 2011 due to data collection problems

** Greenhills Health Centre commenced form submission in September 2011

Key points

The second year of information shows:

- On 31st March 2012, 791 people were registered, 416 with a date of diagnosis in 2010, and 375 in 2011. Twice as many women (252, 67%) as men (122, 33%) were diagnosed with MS in 2011.
- In 2011, 11% of people were supported by an MS Nurse specialist prior to be given their diagnosis. 52% of people newly diagnosed with MS had contact with a MS Nurse specialist within two weeks of diagnosis. This is a 3% improvement on 2010.
- Targeting individual steps may actually realise greater improvement in the referral process. The key result is that in 2011 nationally the time response within 2 weeks was very effective (81%) 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](#) regarding hospital admissions has resulted in a reduction in the amount of information collected by clinical staff leading to a simpler registration form.
- 14 out of 15 MS teams collect information on people with MS in an electronic format over and above information collected by hospital IT systems.
- The responses of the 24 clinicians suggested that there was a consensus that a national electronic collection tool was possible with the right administrative support. They emphasised the need for appropriate clerical input, the collection of a minimum amount of information and simple collection processes as paramount.

The SMR01 database holds records of all inpatient and day case activity in NHS hospitals in Scotland as well as linked data on deaths in Scotland provided by the National Records of Scotland.

The SMR00 database holds records of outpatient attendances in the NHS in Scotland. It provides information about the speciality providing care (for example in the case of MS, neurology or general medical clinics) but not specific diagnostic information.

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.

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 (81%) 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

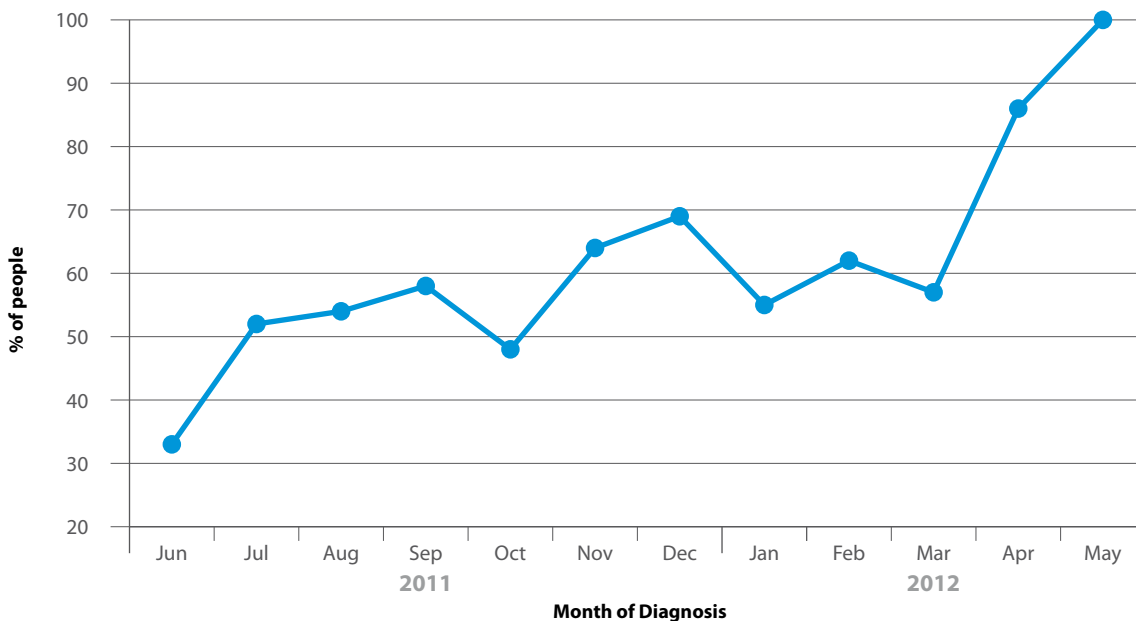
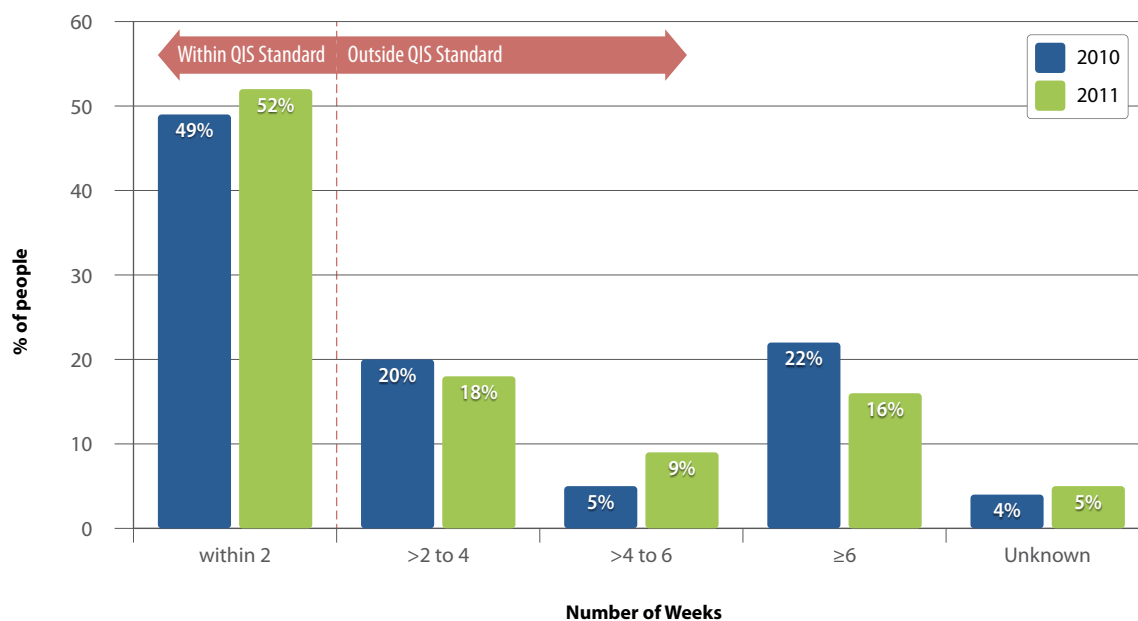


Figure 2 Percentage of people with a new diagnosis of MS in Scotland in 2010 and 2011, by number of weeks from confirmed diagnosis to first contact with MS Nurse



In 2011, 11% of people were supported by MS Nurse specialist prior to be given their diagnosis. 52% (Fig. 2) 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.

Figure 3 Percentage of people with a new diagnosis of MS in Scotland in 2010 and 2011, by number of weeks from confirmed diagnosis to person being referred to MS Nurse

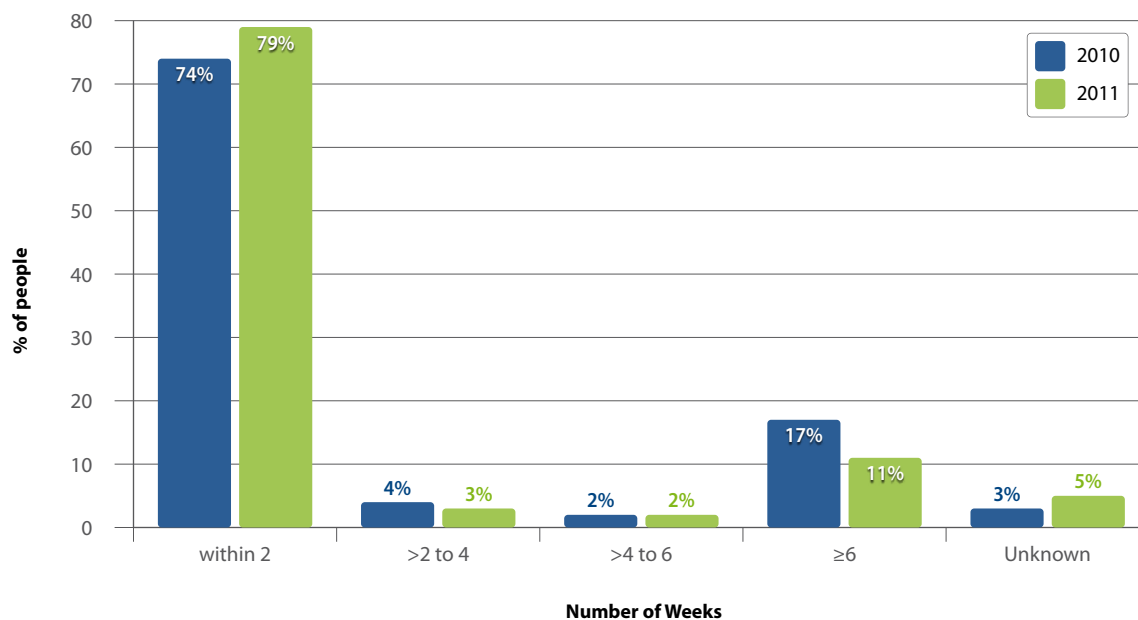


Figure 4 Percentage of people with a new diagnosis of MS in Scotland in 2010 and 2011, by number of weeks from referral to MS Nurse receiving referral

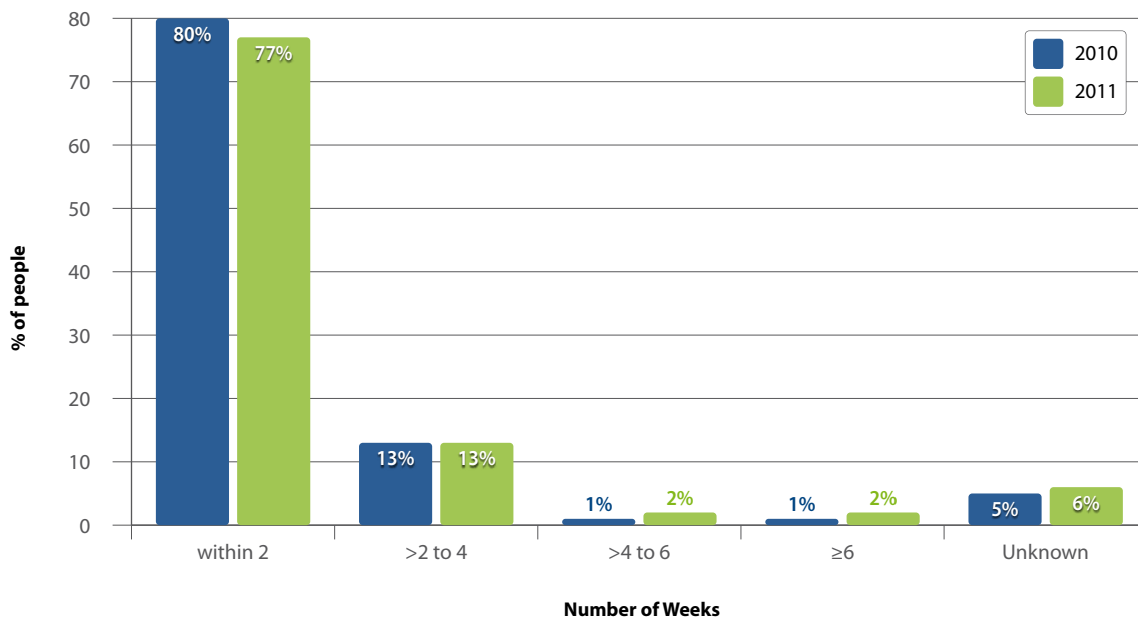
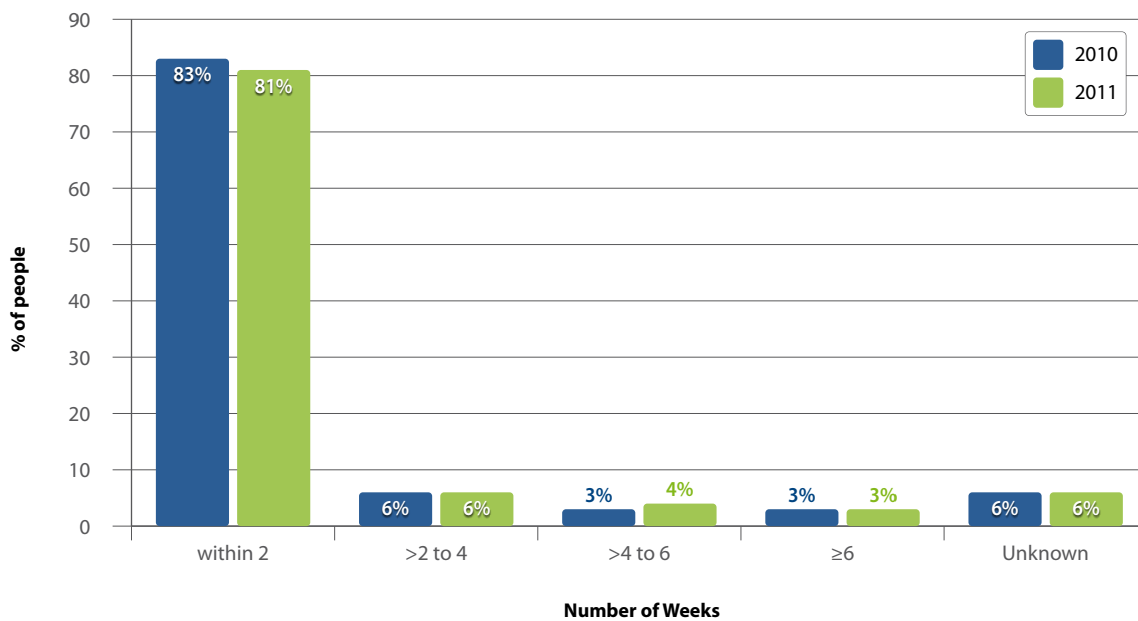


Figure 5 Percentage of people with a new diagnosis of MS in Scotland in 2010 and 2011, by number of weeks from MS Nurse receiving referral to person being contacted by MS Nurse



Section 2 Demographics

A total of 791 people were entered onto the Scottish MS Incidence Register from 1st Jan 2010 to the 31st Dec 2011 (Table 1). Throughout the remainder of this report the term 'people diagnosed' refers to people who were entered onto the Register from 01.01.2010. to 31.12.2011.

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, there may be people who are diagnosed by a general neurologist and not referred to local services or reported to the register. It is hoped that the three monthly report introduced earlier this year will provide MS teams with information that will highlight areas of concern in the MS service referral process, including under referral of people with a new diagnosis of MS to MS teams.

Table 2 Number of people with a new diagnosis of MS in Scotland in 2010 and 2011, reported by Health Board⁺

Health Board	SNAP Report 2000	MS Register 2010	MS Register 2011
Argyll and Clyde*	43	*	*
Ayrshire and Arran	38	17	27
Borders**	11	6	1
Dumfries and Galloway	15	12	16
Fife	35	29	24
Forth Valley	28	17	23
Grampian	53	54	47
Greater Glasgow	91	98	90
Highland	21	26	18
Lanarkshire***	56	46	21
Lothian	77	57	54
Orkney	2	5	5
Shetland	2	4	4
Tayside	39	40	41
Western Isles	3	5	4
Total	514	416	375

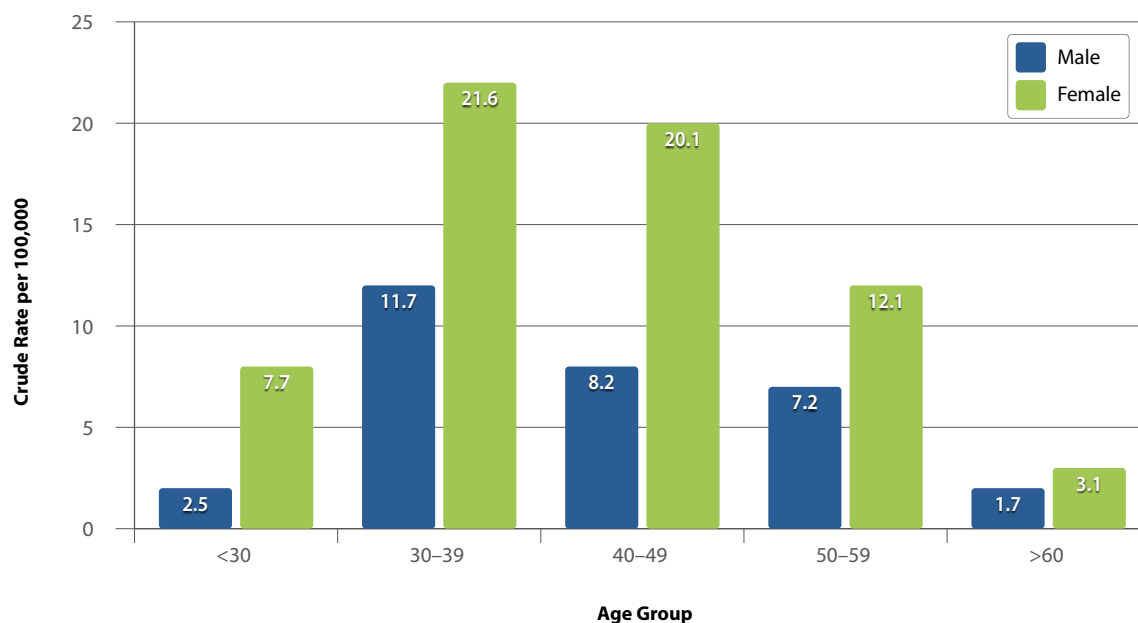
- + SNAP figures quoted are extrapolations based on 2000 population and an incidence rate of 10/100,000/yr
- * Argyll and Clyde - In April 2006, NHS Scotland dissolved the board and transferred its responsibilities to NHS Highland and NHS Greater Glasgow and Clyde
- ** Data for Borders District General is incomplete for 2011 due to data collection problems
- *** Greenhills Health Centre commenced form submission in September 2011

SNAP Report 2000 figures are based on the paper by Rothwell and Charlton (1998) which suggests a crude incidence of definite or probable cases of 10 to 12/100,000/yr in Lothian and Borders. SNAP Report 2000, p.7, suggested:

“Number of possibles exceed number of confirmed cases by a factor of 5, tertiary referral centres with established MS expertise report lower figures.”

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'.

Figure 6 Crude rate per 100,000 of people with a new diagnosis of MS in Scotland in 2010, by gender and age at time of diagnosis



On 31st March 2012, 791 people were registered, 416 with a date of diagnosis in 2010, and 375 in 2011. Twice as many women (252, 67%) as men (122, 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 2010, by gender and age at time of diagnosis

Age Group	Male	Population	Crude Rate	Female	Population	Crude Rate
<30	24	963,284	2.5	71	923,894	7.7
30-39	37	317,304	11.7	71	328,796	21.6
40-49	31	379,511	8.2	83	412,132	20.1
50-59	24	335,472	7.2	43	354,726	12.1
>60	9	534,744	1.7	21	672,237	3.1
Unknowns	1			1		
Overall	126	2,530,315	5.0	290	2,691,785	10.8

* 2 patients could not be reported, because their MS Diagnosis date was not fully known.

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

Figure 7 Percentage of people with a new diagnosis of MS in Scotland in 2010 and 2011, by gender and age at time of diagnosis

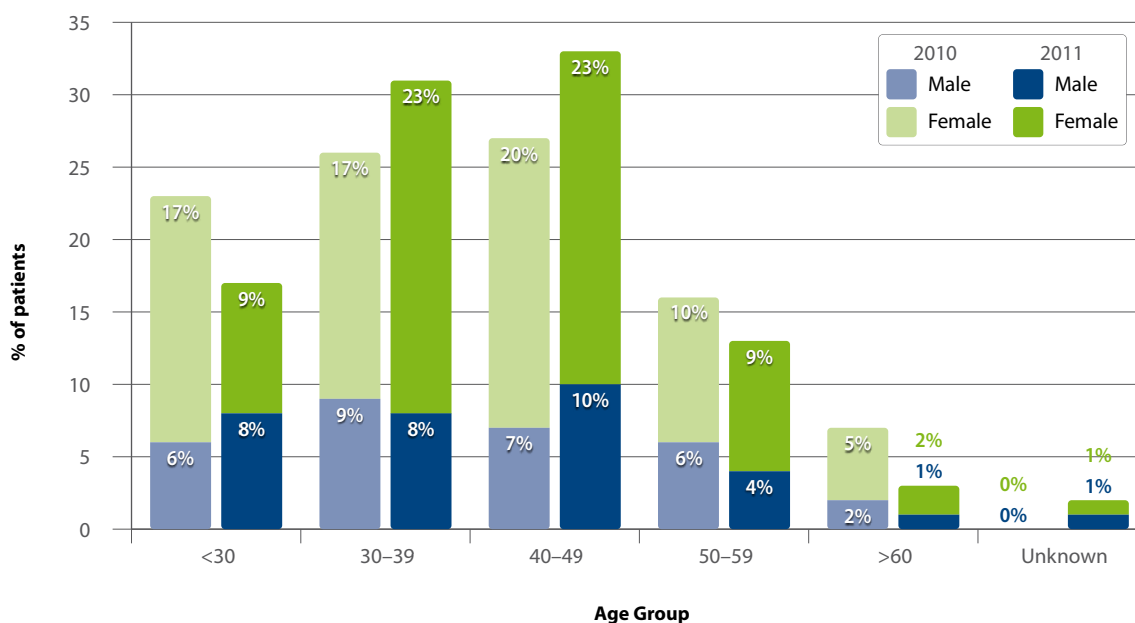
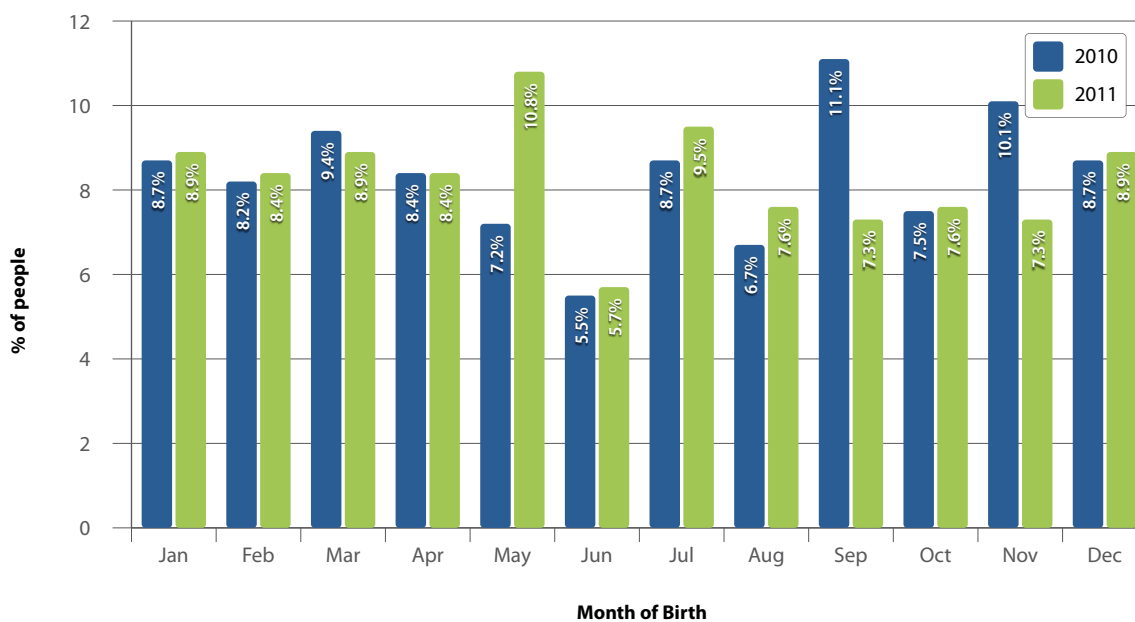


Figure 8 Percentage of people with a new diagnosis of MS in Scotland in 2010 and 2011, by month of birth



There are several papers which suggest there is a relationship between timing of birth, exposure to sunlight and MS. From the above table, the increase in month of births for May in 2011, and September and November in 2010 are not statistically significant. This could be due to the small sample size of only new diagnoses of MS. This requires further investigation.

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 2011. Please note the high number of cases for which information was not disclosed or was not known.

Table 4 Country of Birth

Country of Birth	2010		2011		Total	
	Number	%	Number	%	Number	%
Scotland	180	43.3%	146	38.9%	326	41.2%
Other UK	15	3.6%	19	5.1%	34	4.3%
Other	11	2.6%	12	3.2%	23	2.9%
Unknown / not disclosed	210	50.5%	198	52.8%	408	51.6%
Total	416	100%	375	100%	791	100%

Table 5 Domestic Status

Domestic Status	2010		2011		Total	
	Number	%	Number	%	Number	%
Living alone	54	13.0%	53	14.1%	107	13.5%
Living with spouse / partner	189	45.4%	142	37.9%	331	41.8%
Living with family	115	27.6%	76	20.3%	191	24.1%
Other	2	0.5%	0	0%	2	0.3%
Unknown / not disclosed	56	13.5%	104	27.7%	160	20.2%
Total	416	100%	375	100%	791	100%

Table 6 Employment Status

Employment Status	2010		2011		Total	
	Number	%	Number	%	Number	%
Regular paid employment	225	54.1%	209	55.7%	434	54.9%
Self employed	19	4.6%	8	2.1%	27	3.4%
Looking after home/family	23	5.5%	11	2.9%	34	4.3%
Unemployed	23	5.5%	34	9.1%	57	7.2%
In formal education	22	5.3%	8	2.1%	30	3.8%
Retired	17	4.1%	6	1.6%	23	2.9%
Sick/disabled (permanent or temporary)	28	6.7%	17	4.5%	45	5.7%
Unknown / not disclosed	59	13.9%	82	21.9%	141	17.8%
Total	416	100%	375	100%	791	100%

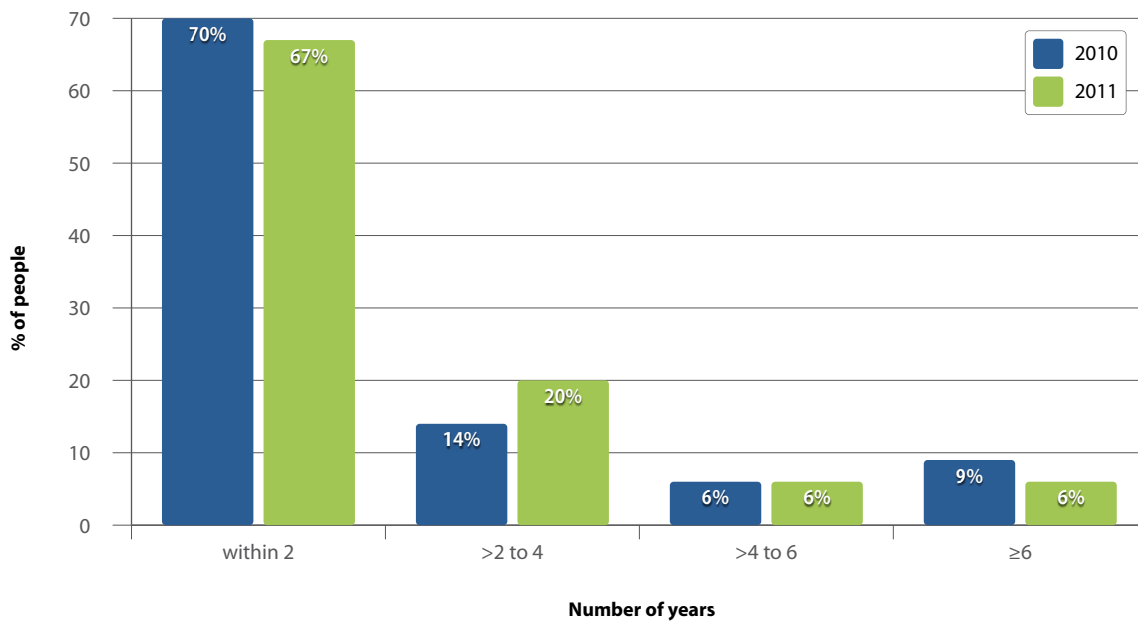
Table 7 History of MS within Family

MS Family History	2010		2011		Total	
	Number	%	Number	%	Number	%
History of MS in family	44	10.6%	35	9.3%	79	10.0%
No History of MS in family	296	71.2%	259	69.1%	555	70.2%
Unknown / not disclosed	76	18.3%	81	21.6%	157	19.8%
Total	416	100%	375	100%	791	100%

Please note:

Since October 2011, completion of the following fields have been made optional: 'Country of Birth', 'Domestic Status', 'Employment Status', 'History of MS in Family'

Figure 9 Percentage of people with a new diagnosis of MS in Scotland in 2010 and 2011, 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 142 proforma (34%) in 2010 to 172 (46%) in 2011. 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. 67% of people diagnosed with MS in 2011 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 between the first 18 months (01.01.10 until 30.06.11) of the Scottish MS Register. Time period was from 1997 until September 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.

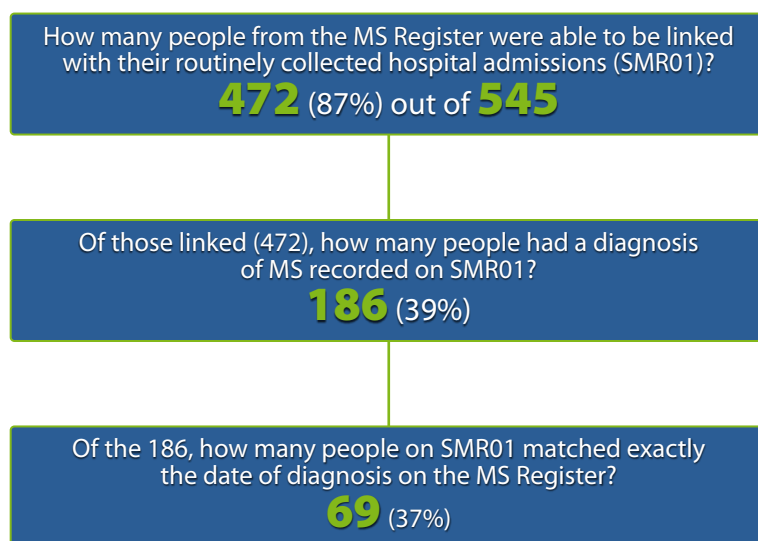
The register provided patient identifiable information (for example CHI is present in all but 2 people) that enabled the linkage process to match the two sets of information. The Scottish MS Register unique number acted as the identifier between the MS Register and the hospital admission (SMR 01) records. 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.

The SMR01 database holds records of all inpatient and day case activity in NHS hospitals in Scotland as well as linked data on deaths in Scotland provided by the National Records of Scotland.

The SMR00 database holds records of outpatient attendances in the NHS in Scotland. It provides information about the speciality providing care (for example in the case of MS, neurology or general medical clinics) but not specific diagnostic information.

Results

545 people were reported to the Scottish MS Register between 01.01.10 until 30.06.11.



Of the 545, the number of patients from the Scottish MS Register whose data was able to be linked with SMR01 was 472 (87%), with 186 (39%) out of 472 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 out patient setting.

The date of Diagnosis of MS on SMR01 was recorded differently from the date of diagnosis on the register information system in 117 (63%) out of 186 people. Further investigation of the 117 people revealed that 7 (6%) of the diagnostic dates on SMR01 married up with the date of investigation of MRI, 71 (61%) with the date of the lumbar puncture. The difference between the two sources of information is the use of different recording definitions. i.e. register date of diagnosis is the date at outpatient clinic when all test results were available to discuss with the patient. 39 (33%) had no date that could explain the difference in diagnosis between the two sources of information. Further investigation is required of the 73 people on the MS Register who were not matched with SMR01 information and the 39 who had no date that explained the different date of diagnosis between the two sources of information.

The rest of this section will now talk about the 472 people who were matched with the hospital data. For the 472 people, between 1997 and September 2011, there was a total 1736 admissions to hospital.

Figure 10 How many hospital admissions did people with MS have before and after MS Register date of diagnosis?

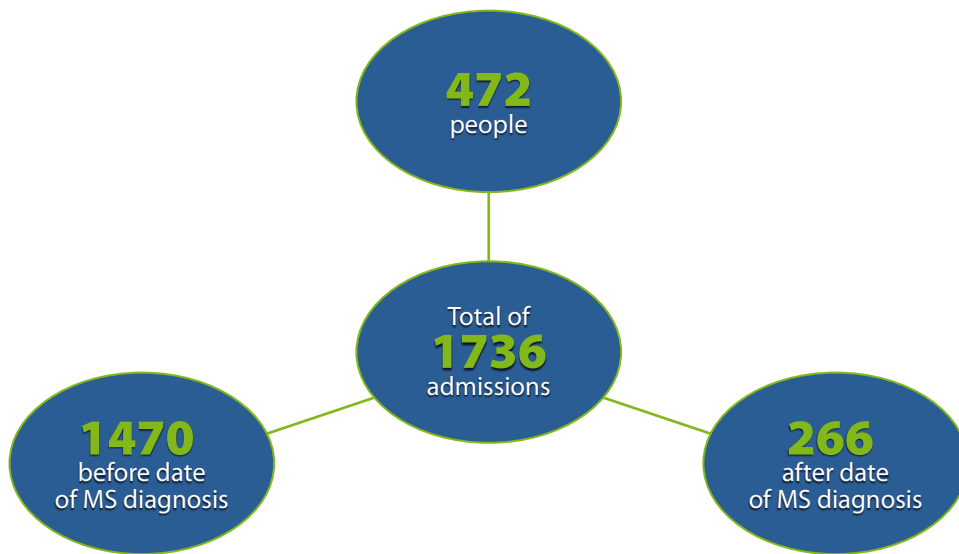
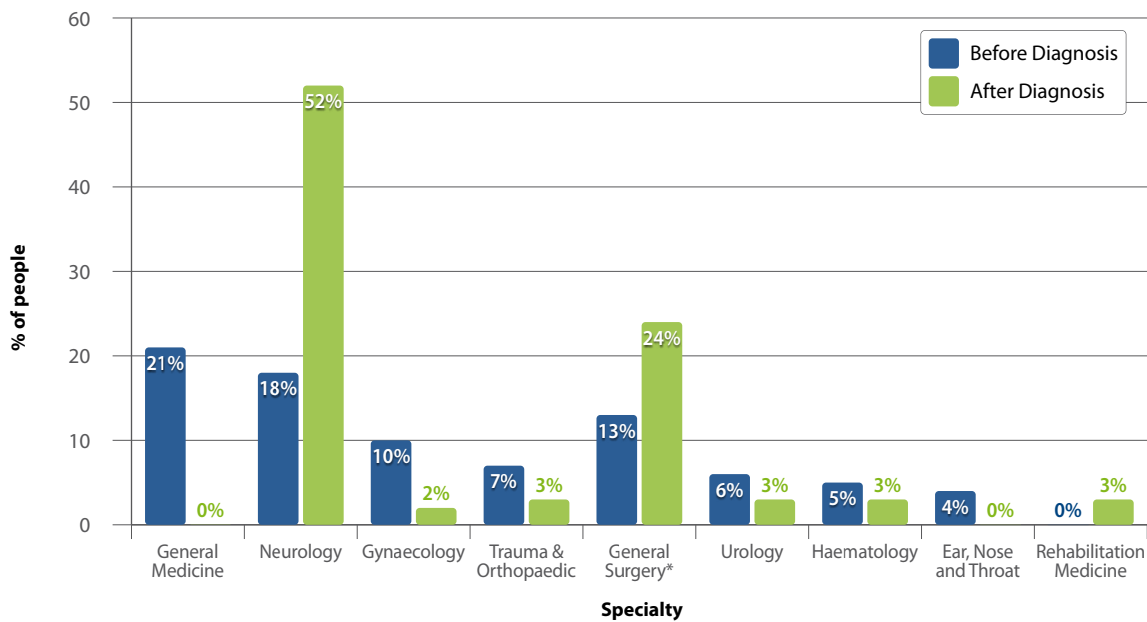


Figure 11 What type of speciality were people under the care of, before and after their date of diagnosis?



* excludes Vascular Surgery

This information will add additional information that the Scottish MS Register does not collect, only information prior to diagnosis in an outpatient setting was collected until June 30th 2011.

Over time this information may provide insight into the type of interactions with healthcare professionals within a hospital setting encountered by people with MS.

Section 4 IT Survey

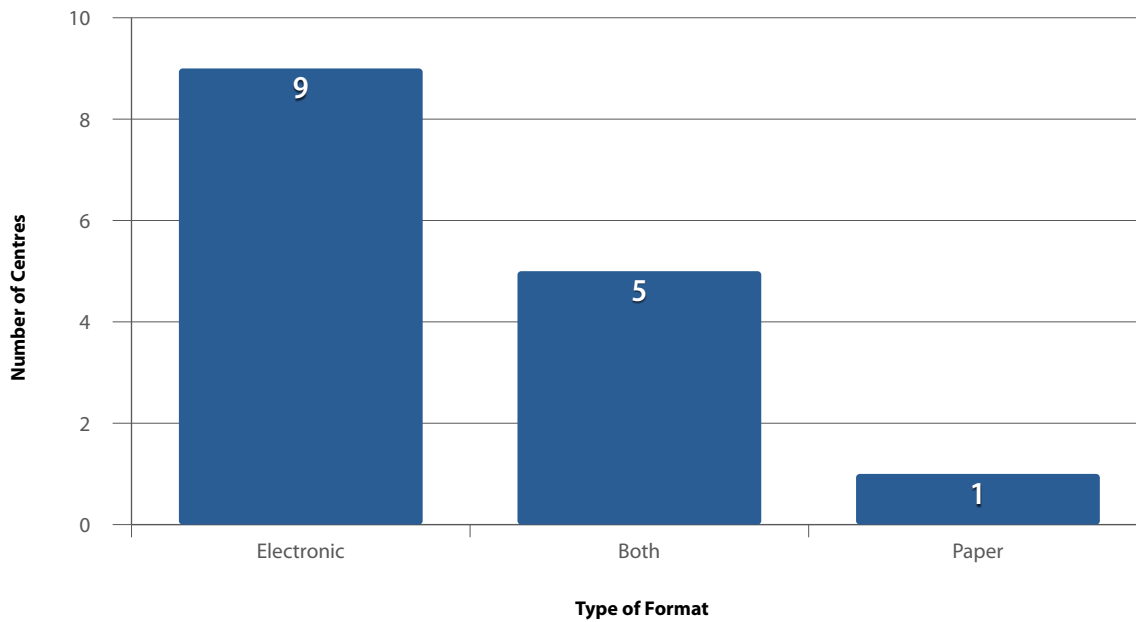
A questionnaire was designed and conducted in England, Ireland and Wales as part of the MS Society UK Register Project. The questionnaire was designed to find out the type of electronic information collected by clinical staff about their patients with MS. The survey design in Scotland was expanded to incorporate the question; at the present time, is it feasible to develop a national information system of every person with MS in Scotland. Interviews with MS Nurse specialists, information system administrators, and consultant neurologists were conducted by telephone or in person during May to August 2011. Follow up emails/telephone calls were carried out for clarification and updating of information in April 2012. The survey was undertaken to find out the answers to the following questions:

1. Do MS clinicians collect information in an electronic format over and above information collected by clinical healthcare IT system?
2. If yes,
 - what electronic format is the information collected;
 - what is the reason the information is collected;
 - what type of information is collected i.e. dates, drugs, and clinics?
3. When did they start collecting the information?
4. Is it possible to develop a national electronic system to collect information on every person with MS in Scotland?

Table 8 The 15 participating MS Team Sites / NHS Board

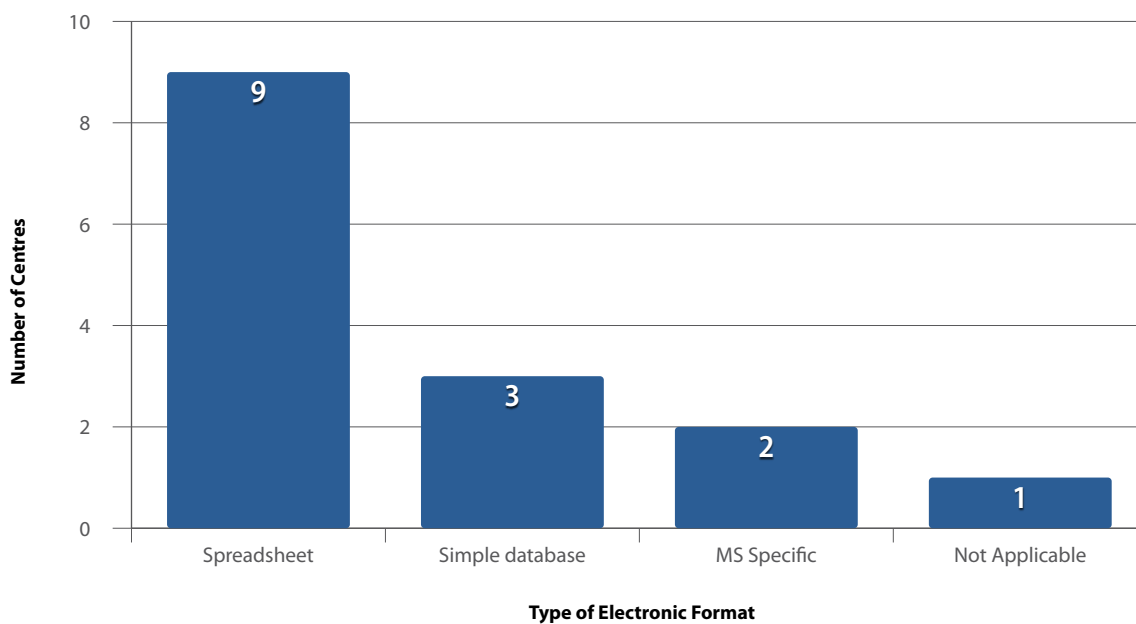
Aberdeen Royal Infirmary, Grampian	Gilbert Bain Hospital, Shetland
Balfour Hospital, Orkney	Institute of Neurological Science, Glasgow
Borders District General Hospital, Borders	Ninewells Hospital, Tayside
Douglas Grant Rehabilitation Centre, Ayrshire & Arran	Raigmore Hospital, Highlands
Dumfries & Galloway Royal Infirmary, Dumfries & Galloway	Victoria Hospital, Fife
Fife Rehabilitation Centre, Cameron Hospital, Fife	Western General, Edinburgh
Forth Valley Royal Hospital, Forth	Stornoway Health Centre, Western Isles
Greenhills Health Centre, Lanarkshire	

Figure 12 What type of format does your centre use to collect and manage data?



14 out of the 15 MS teams are collecting information in an electronic format over and above information collected by clinical healthcare information systems.

Figure 13 In what type of electronic format do you collect information?



- 2 are utilising a MS specific information collection tool (iMed).
- Further 2 have iMed installed but no administrative staff to support information input.
- 11 have MS Excel or MS Access spreadsheets.
- 1 hospital has paper only at present but has plans to implement iMed when additional administrative support is provided to MS team.

Why are you collecting information?

Reasons given for collecting information were:

- MS specific information not routinely collected on hospital system.
- Spreadsheet to manage people who have Disease Modifying Therapy (DMTs), return clinic appointments and home visits.
- To start collecting information that will help improve services, e.g. EDSS, MS specific symptoms and management, local reports.

Have you imported earlier records into your current system?

This question was relevant to 5 hospitals.

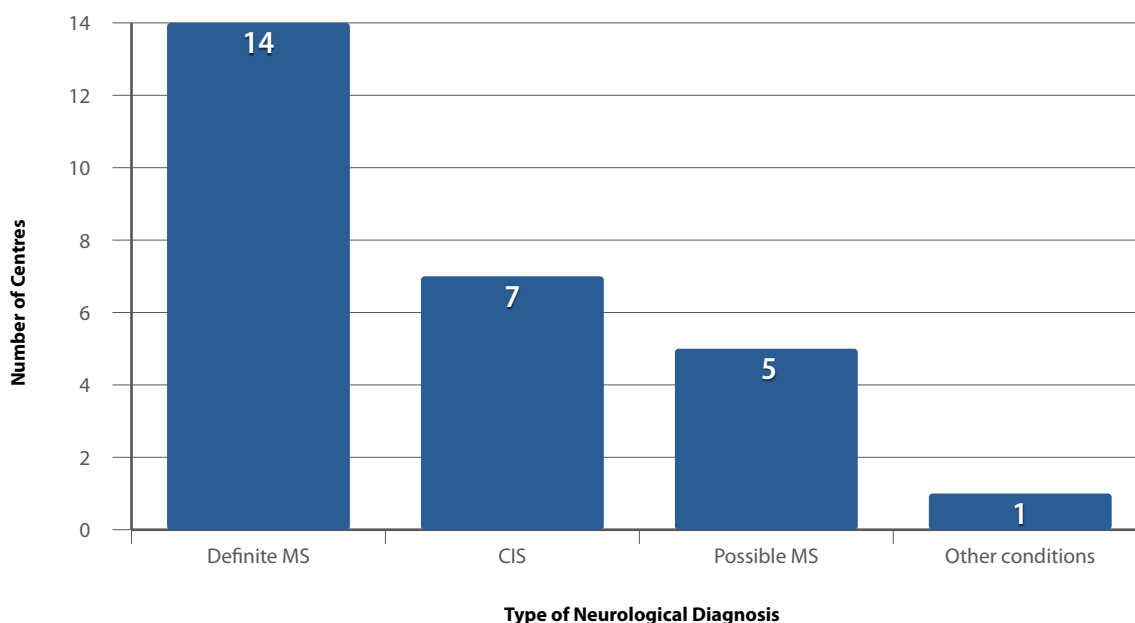
- 2 hospitals have imported demographics only.
- 2 hospitals are working between 2 systems at present, but all information will eventually be in the new system.
- 1 hospital requires updating of the system as there has been no one in post in the last 2 years.

Table 9 How many patient records are stored on your system?

Number of Patient Records	Number of Centres
0 to 200	3
201 to 400	2
401 to 600	2
601 to 800	1
801 to 1000	3
>1000	1
Total	12

The earliest system was set up in 1997, with 6 systems being set up from 2009 to the present time.

Figure 14 What type of neurological diagnosis does your database collect?



- All 14 centres collect information on people with a definite diagnosis of MS.
- 7 centres collect information on people with a diagnosis of a Clinical Isolated Symptoms.
- 5 centres collect on people with a possible diagnosis of MS.

How is the data entered and by whom?

- 1 is entering prospectively, all others retrospective.
- 3 have administrative support for data entry.
- Remaining 10 completed by clinical staff.

Do you have plans to introduce a new system?

- 2 hospitals have implemented iMed but do not have the administrative support to maintain the system.
- Several hospitals are thinking about implementing iMed and are awaiting the result of the other 2 hospitals experience.
- 3 have implemented new systems recently and are happy with the new system.
- 1 hospital would only consider implementing any new system if it was properly resourced and maintained with appropriate staffing.

What are your views on developing a national electronic system to collect information on every person with MS in Scotland?

This question was also asked of 11 neurologists with an interest in MS.

Several of the clinicians praised the process that the MS Society Scotland had adopted in the development of the Scottish MS Register. One clinician stated that the relevant people had been involved, clinicians had been encouraged to participate, assurances had been made that the information would belong to clinicians, and the lessons learnt from previous experiences with setting up an information system had been taken on board. Majority of clinicians had emphasised the need for appropriate clerical input, the simplicity of the information set and information collection processes are paramount.

The responses of the 24 clinicians were that there was a consensus that a register with every person in Scotland with MS was possible with the right administrative support. 2 of the neurologist stated that it would also require to be 'manageable' i.e. collect enough information to be able to answer clinical questions that current hospital electronic systems are unable to do, but not onerous that information is 'collected for someone's special interest' and not necessarily for the benefit of the patient.

