

Scottish Multiple Sclerosis Register  
National Report 2015

Scottish  
MS Register





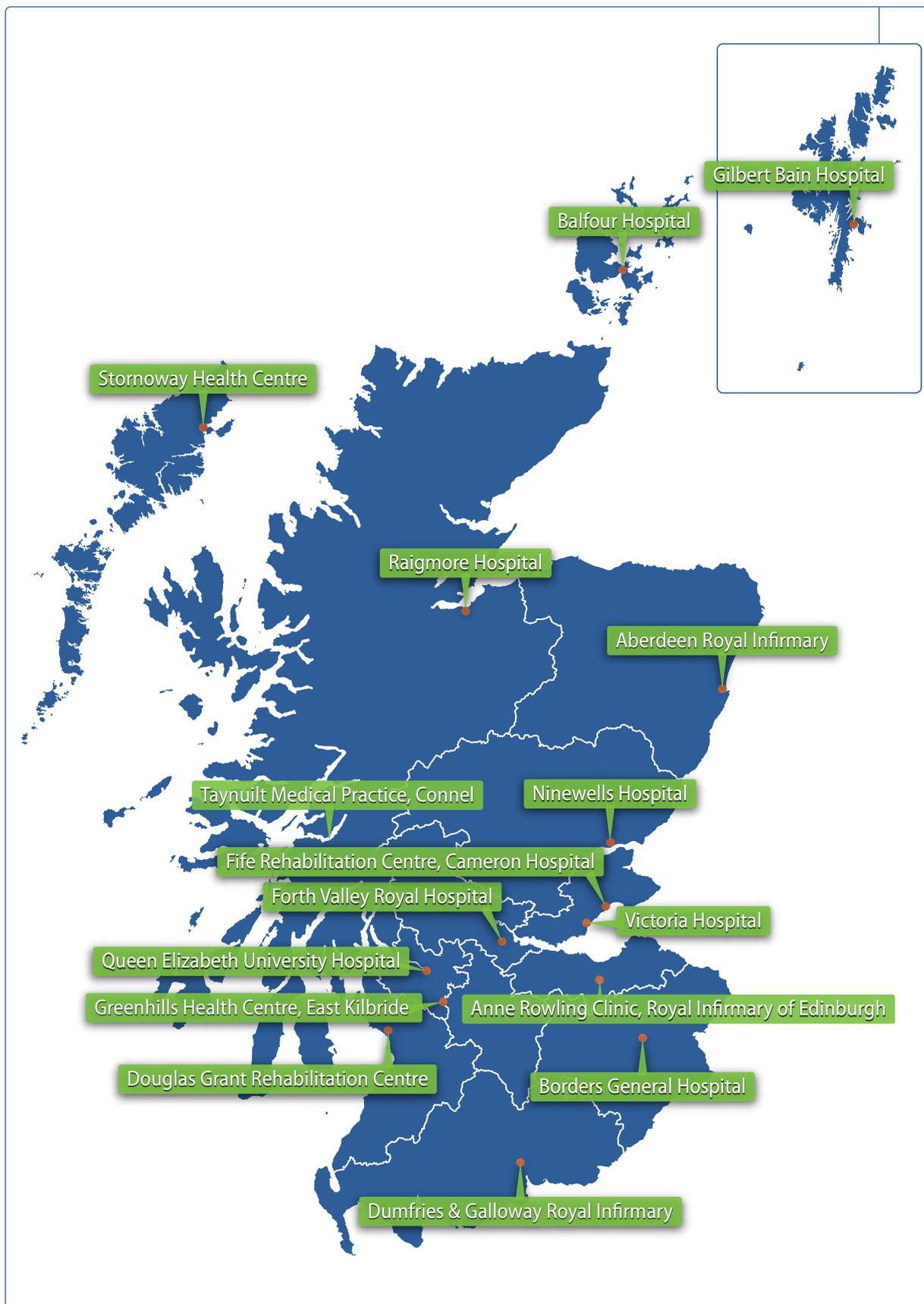
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# Map of Scotland showing all MS service providers by Health Boards who contribute to the Scottish MS Register



# Acknowledgements

The Steering Group of the Scottish MS Register (SMSR) would like to thank the staff, in particular the MS nurses 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 in table 1 below.

**Table 1** List of clinical leads for each hospital/unit

Health Board	Hospital / Unit	Lead Consultant
NHS Ayrshire & Arran	Douglas Grant Rehabilitation Centre, Irvine	Paul Mattison
NHS Borders	Borders General Hospital, Melrose	David Simpson
NHS Dumfries & Galloway	Dumfries & Galloway Royal Infirmary	Ondrej Dolezal
NHS Fife	Cameron Hospital, Windygates Victoria Hospital, Kirkcaldy	Lance Sloan Uwe Spelmeyer
NHS Forth Valley	Forth Valley Royal Hospital, Larbert	Christian Neumann
NHS Grampian	Aberdeen Royal Infirmary	Margaret-Ann MacLeod
NHS Greater Glasgow & Clyde	Institute of Neurological Science, Queen Elizabeth University Hospital	James Overell Stuart Webb
NHS Highland	Raigmore Hospital, Inverness	Javier Carod-Artal
NHS Lanarkshire	Greenhills Health Centre, East Kilbride	James Overell
NHS Lothian	Royal Infirmary of Edinburgh	Belinda Weller (Chair)
NHS Orkney	Balfour Hospital, Kirkwall	<sup>1</sup>
NHS Shetland	Gilbert Bain Hospital, Lerwick	James Unsworth
NHS Tayside	Ninewells Hospital, Dundee	Jonathan O'Riordan
NHS Western Isles	Stornoway Health Centre	Saif Razvi <sup>2</sup>

## Notes:

- 1 For diagnosis information, please contact Moira Flett, MS Nurse Specialist as there is no MS Clinical Lead in NHS Orkney. Patients are managed by clinicians in NHS Grampian.
- 2 Diagnosis made by a General Neurologist from Institute of Neurological Science, Queen Elizabeth University Hospital.

The Register co-ordinators for each of the hospitals/ units are listed in table 2 below.

**Table 2** List of Register Co-ordinators for each hospital/ unit

Health Board	Hospital / Unit	Register Co-ordinator
NHS Ayrshire & Arran	Douglas Grant Rehabilitation Centre, Irvine	Jacqueline Downs
NHS Borders	Borders General Hospital, Melrose	Lorna Rogerson
NHS Dumfries & Galloway	Dumfries & Galloway Royal Infirmary	Elizabeth Clark
NHS Fife	Cameron Hospital, Windygates	Debbie McCallion
NHS Forth Valley	Forth Valley Royal Hospital, Larbert	Madeleine Steele
NHS Grampian	Aberdeen Royal Infirmary	Mairi Maguire
NHS Greater Glasgow & Clyde	Institute of Neurological Science, Queen Elizabeth University Hospital	Lynn Cherry
NHS Highland	Raigmore Hospital, Inverness	Anne Stewart Cheryl Howe
NHS Lanarkshire	Greenhills Health Centre, East Kilbride	Mhairi Coutts
NHS Lothian	Royal Infirmary of Edinburgh	Matthew Justin
NHS Orkney	Balfour Hospital, Kirkwall	Moira Flett
NHS Shetland	Gilbert Bain Hospital, Lerwick	Elizabeth Clarke
NHS Tayside	Ninewells Hospital, Dundee	Pamela Walker
NHS 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.

# Foreword



The Scottish Government remains committed to improving services for people living with neurological conditions like MS.

The Scottish MS Register, now in its fifth year, is a unique database of confirmed diagnoses of patients with MS. The success of collecting data is due to the active participation, commitment and support of the clinical teams in all the NHS Boards in Scotland.

The Register has an important role in helping us understand the epidemiology and incidence of MS across Scotland. Its aim is to help inform service planning and provision to ensure equity of access to services for everyone diagnosed with MS regardless of where they live in Scotland.

The Register has encouraged and enabled MS Clinical Nurse Specialists to look at how they can use the data to drive improvement in services locally. I would encourage them to continue this good work and to share best practice across Scotland.

I am pleased to see in this year's report that there has been a steady year on year increase in the number of newly diagnosed patients having contact with a MS Clinical Nurse Specialist within 10 working days of diagnosis. This is encouraging and important for those newly diagnosed patients.

I would like to commend all those involved in the Register for their continuing hard work and their important contribution to the care of MS patients across Scotland.

**Dr Catherine Calderwood**  
Chief Medical Officer

# 1. Introduction

It gives me great pleasure to introduce the fifth year National Report of the SMSR.

The Register was established in 2010 and has collected data related to new diagnoses of MS across Scotland since then. The aim of the 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 MS nurses, clinicians and others to submit data on all people with a confirmed diagnosis of MS via a standard proforma.

The Register has achieved the collection of data for over 2000 patients with a verified diagnosis of MS and this information provides important epidemiological data which will be used to facilitate research into reasons for the high incidence and prevalence of MS in Scotland. The information is also being used to improve health services for people with MS by comparing the data related to MS diagnoses with national standards for MS care to identify areas where improvement in service delivery and timely patient care are required.

The responsibility for the oversight of the Register rests with the Register Steering Group with representation including neurologists, primary care clinicians, MS nurses, Allied Health Professionals (AHP), voluntary sector and patient representatives as well as staff from the Information Services Division (ISD) of National Services Scotland (NSS) who co-ordinate the Register nationally, validating and reporting on the data.

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 have been made at national and international meetings and several research fellows have been identified who will undertake further epidemiological research (see section 5 for more details).

I would like to thank all of the MS nurses and clinicians who generously provide their time and effort to report information about newly diagnosed people with MS to the Scottish MS Register. I would also like to thank Hazel Dodds who has joined us as the Clinical Co-ordinator along with her analyst colleagues for the energy and enthusiasm that they have injected into the project in recent months.

As the five year data are presented I am optimistic that this unique Scottish endeavour will continue to provide information which will be used to improve the quality of life of people with MS.

**Dr. Belinda Weller**

Neurologist  
Chair SMSR Steering Group

## 1.1 Contributions to this report

This year's report has been written by members of the Report Writing Sub-Group of the SMSR Steering Group with contributions from colleagues within Health Boards and patients across Scotland. In chapter 6 we present summaries from Health Boards who have made innovative changes to practice leading to improvement in delivery of care for MS patients.

## 1.2 Organisational structure of the Scottish MS Register

The Scottish MS Register is a national Register within the Scottish Healthcare Audits of ISD of NHSNHS. The Register has its own Steering Group of key stakeholders who provide strategic direction and clinical input to the Register team optimising the use of the data. The organisational structure of the SMSR is:

- **Dr Belinda Weller**—Chair of the Steering Group
- **Dr Paul Mattison** – Chair of the Report Writing Sub-group
- **Dr Jonathan O’Riordan** – Chair of the Research Sub-group
- **Hazel Dodds**—Senior Nurse (Clinical Co-ordinator of the SMSR)
- **Amanda Gilmour**—Information Analyst
- **Martin O’Neill**—Principle Analyst

Funding is received from the Scottish Government for the central coordination of the SMSR. Each Health Board is expected to continue to collect data for the SMSR. Specialist MS nurses and others employed in each Health Board acting as ‘auditors’ collect the data for the Register. Staffing levels vary widely between hospitals. ‘Auditors’ responsibilities include case ascertainment, data collection, completion and submission of forms. Data validation is completed locally at source and also by the central team on receipt of completed forms and during analysis.

## 1.3 This report

This year's report includes data for 2014 for Scotland overall and for each individual hospital/ unit managing MS patients in Scotland. The data presented in this report are for patients newly diagnosed with MS. This report also presents trend data from the last five years.

In summary, there were **431** patients newly diagnosed with MS in Scotland in 2014. Every effort has been made by the central team and the MS nurses to improve case ascertainment and provide a true reflection of incidence of MS in Scotland in 2014 though it is acknowledged that some cases may not have been added to the SMSR for a variety of reasons.

Throughout 2014 the SMSR team continued to review the analysis of the data collected and have modified definitions when necessary, therefore **calculations in this year's report may not match exactly those presented in previous reports**. Scottish, Health Board and individual hospital data are displayed in charts and tables throughout the report and are also available on the SMSR website (<http://www.msr.scot.nhs.uk/Reports/Main.html>).

## 2. Progress

### Collection of data:

Forms continue to be completed by the MS nurses or colleagues in Health Boards and were submitted by post to the central team on an adhoc basis. This process has been modified to improve efficiency with colleagues being asked to submit forms once every quarter. It has been agreed that forms can also be submitted securely electronically using scanning.

The potential for an IT solution for data collection continues to be investigated. This would streamline and improve the accuracy and efficiency of data collection.

### Primary care data:

A small project has been undertaken in NHS Lanarkshire to look at the recording of MS diagnosis in GP practices, this is described in more detail in chapter 4.

### Data items:

The SMSR now has five years of data. It was agreed by the Steering Group that it was time to review and update the SMSR dataset. This process commenced in June 2015 and it is planned that collection of the new dataset will commence in January 2016.

### Routine reporting:

Distribution of Quarterly Reports to MS nurses and Clinical Leads reflecting activity for the previous quarter and performance against one of the national Neurological Standards (15.2) continues.

A review of the content of the Quarterly Reports is underway and will come into place when the new data collection starts in 2016.

The aim of future reporting is to establish quality feedback reports. These reports will monitor the performance of hospitals/ Health Boards against nationally agreed neurological standards. For example, as noted above the SMSR currently reports against standard 15.2 – the proportion of patients who are contacted by an MS Nurse within 2 weeks of diagnosis. People with MS whose care does not meet standard 15.2 are identified for local review. The future plan for the SMSR is to follow up this process to determine why care does not meet this standard and identify actions with the Health Board area to improve on this.

### SMSR National Meeting:

The first SMSR National Meeting will be held on Tuesday 8th September 2015 at the Carlton Highland Hotel, North Bridge, Edinburgh to coincide with the publication of this report. Further information can be found on the SMSR website (<http://www.msr.scot.nhs.uk>).

### Quality Assurance:

A high standard of data quality is essential to ensure that the SMSR data are accurate, consistent and comparable across time and between hospitals. This will ensure that decisions for change to improve quality of care and service provision at hospital, Health Board and national level are based on correct information. Without quality, it would be impossible to interpret results with any accuracy or conviction.

The data quality processes undertaken by the SMSR are incorporated into the following:

**At point of data collection:**

It is expected that those collecting the SMSR data will do so accurately and consistently as defined by the SMSR protocols and will check/ validate forms prior to submission to the central team.

**Central validation:**

Data are checked by the central team when forms are received and during the analysis process. Any anomalies are fed back to the 'auditors' and corrected as necessary.

**Case note validation:**

It is planned to introduce case note validation to the SMSR in the next year. This will be carried out by Quality Assurance Managers from the Scottish Healthcare Audit team. An agreed proforma and process is being developed centrally. This will allow confirmation of the accuracy of the SMSR data. Findings of case note validation will be shared with the 'auditors' with a short summary of outcomes provided in the 2016 SMSR Annual National Report.

**Case ascertainment:**

It is planned to carry out routine quarterly checks of the number of patients added to the Register from each hospital/ clinic. This will involve liaison between the central team and the 'auditors'. This will improve case ascertainment and will avoid a 'catch up' at the end of the calendar year.

**The future:**

The SMSR has identified that there is a need to explore and develop, either through audit or research, areas to improve patient management and services. A Research Sub-group was established in 2015, chaired by Dr Jonathan O'Riordan. Forthcoming Steering/ Research Sub-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 Therapies (DMTs);
- Review additional HIS Neurological Standards relevant to MS and the potential to include them in the core dataset;
- Development of a research portfolio; and
- Review the potential to run sprint audits of areas of interest, e.g. relapse management pathways.

For further details of the initial work of the Research Sub-group and plans for the future please refer to chapter 5.

## 3. Results

### 3.1 Case ascertainment

The SMSR central team and the 'auditors' have increasingly cross checked their SMSR data with routinely collected local data. Any increase in the number of patients diagnosed with MS in 2014 may reflect improvement in case ascertainment, rather than increasing numbers of patients diagnosed with MS. As noted in chapter 2, continuing to improve the checking process should lead to more robust case ascertainment and clearer incidence reporting of MS in Scotland.

However whilst strenuous efforts have been 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 caution.

### 3.2 Summary & key findings

As noted previously the SMSR began data collection in 2010. This report covers the period of the first five years of such data collection.

During the period covered by this report 2164 new cases of MS have been reported and included on the Register database. This represents a mean incidence rate over the five year period of 8.2 per 100,000 per year, a figure somewhat lower than those previously reported from historical regional based reports, but nonetheless still representing a significantly higher rate of MS than is seen in most other countries and in particular neighbouring countries in the UK.

As noted in section 3.1 there are a number of potential explanations for the lower than anticipated incidence figures. There are still some concerns over completeness of case reporting and data capture and measures are being taken to examine ways of improving data capture and also utilisation of primary care data to provide a comparator for validation of the numbers being reported to the Register. Initiatives involving data from primary care in NHS Ayrshire & Arran and NHS Lanarkshire are described in section 4 of this report.

Alternatively it may be the case that incidence rates are genuinely falling within Scotland compared to previously reported figures. McKenzie et al (2013)<sup>1</sup> undertook a UK wide General Practice based study and reported a 1.51% mean annual reduction rate in incidence over the period 1990-2010.

Irrespective of these considerations the number of cases now contained within the Register will permit important audit and research projects to be undertaken to examine aetiological factors which may contribute to the high rates of MS in Scotland and also to look at access to Disease Modifying Therapies (DMT) and availability of appropriate input from multi-professional teams as outlined in the Healthcare Improvement Scotland (HIS) standards of care document<sup>2</sup> relating to MS.

The sex ratio of newly diagnosed patients with MS cumulatively over the five year period was 2.27:1 females to males. There was no evidence of any trend toward increasing numbers of females to males, contrasting with studies from other parts of the world which have suggested a significant shift in the female to male ratio Simpson et al (2012)<sup>3</sup> and Trajano et al (2013)<sup>4</sup> reporting such a trend in the UK and Northern Europe respectively.

No clear cut association between month or season of birth and increased risk of MS is demonstrated over the five year period which is at odds with previous studies which have suggested an increased incidence rate in those born in the summer months. Caution must however be exercised in interpreting these data which will require further analysis with respect to seasonal adjustment of national birth rates and comparison with sibling birth order.

This report pleasingly demonstrates a continued improvement in implementation of HIS standard 15.2 (see section 3.21) which has been part of the reporting process and which relates to contact with a MS nurse within 10 working days of a confirmed diagnosis. The figure for 2014 shows that 63% of patients had such contact compared with 56% in 2013 an improving trend that has been noted in the past three annual reports. Delays in referral to the MS nurse account for a substantial part of the delay in those not meeting this standard reflected in the figure of 85% of patients being contacted once the referral had been received.

There does however remain scope for improvement in communication from the diagnosing clinician to the MS nurse; currently there is considerable variation geographically within different centres in relation to this.

Looking forward the role of the Register will evolve to improve case ascertainment and case verification via audit of hospital records. There will be additional audit projects in relation to compliance with an increased number of the HIS MS standards and access to the data contained within the Register will be offered to MS researchers with the approval of the SMSR Steering Group Research Sub-group and following Information Request protocols within ISD. The Register will thus be achieving the three principal aims that were set at its inception, building up a comprehensive picture of the epidemiology of MS throughout Scotland, informing service planning and provision to ensure equity of access to services for all patients diagnosed within Scotland regardless of geography or Health Board of residence and directing research towards answering the crucial question as to why Scotland has the unenviable reputation of being the world's multiple sclerosis capital.

### 3.21 Introduction to NHS HIS Neurological Standards

Following diagnosis, people with MS are offered a referral to a MS nurse. Clinical Standards for Neurological Health Services were produced by NHS Quality Improvement Scotland (NHS QIS, now HIS) in October 2009.

Standard 15: Diagnosis of MS states: the Health Board provides a co-ordinated MS diagnosis service with access to a multidisciplinary team experienced in the diagnosis of MS.

The rationale for this is: timely and ready access to any necessary investigation resources is essential to promote a more efficient and effective diagnostic process for patients with suspected MS. Patients may require support from the multidisciplinary team throughout the diagnostic process

Essential criteria 15.2 states that contact with a MS Clinical Nurse Specialist is offered at diagnosis to patients with MS and that contact is made within 10 working days of the diagnosis.

There is a strong and recurring theme running throughout all of the results presented in relation to HIS standard 15.2 which highlights a need to improve methods of communication between the diagnosing neurologist and MS nurse colleagues if the standard is to be met. It is very clear that MS nurses do an extremely good job in making contact with a high percentage of newly diagnosed patients once they are made aware of the diagnosis. Undoubtedly progress is being made with evidence of year on year improvement since 2012 in the numbers meeting the standard but overall the figure of 63% remains disappointing. Those centres with better compliance should share their practices with less well performing centres and in particular attention needs to be paid to the means by which nurse specialists are alerted to newly diagnosed patients. The traditional medical model of a Consultant clinic letter being sent after dictation and typing leads to inherent delays, with in many cases the referral being received by the MS nurse well beyond the two week window specified within the HIS standard.

The steady improvement seen in the numbers meeting this standard however is encouraging and a challenge for the Register going forward will be to continue to demonstrate improvement in standard 15.2 and to incorporate monitoring of additional HIS standards in relation to MS.

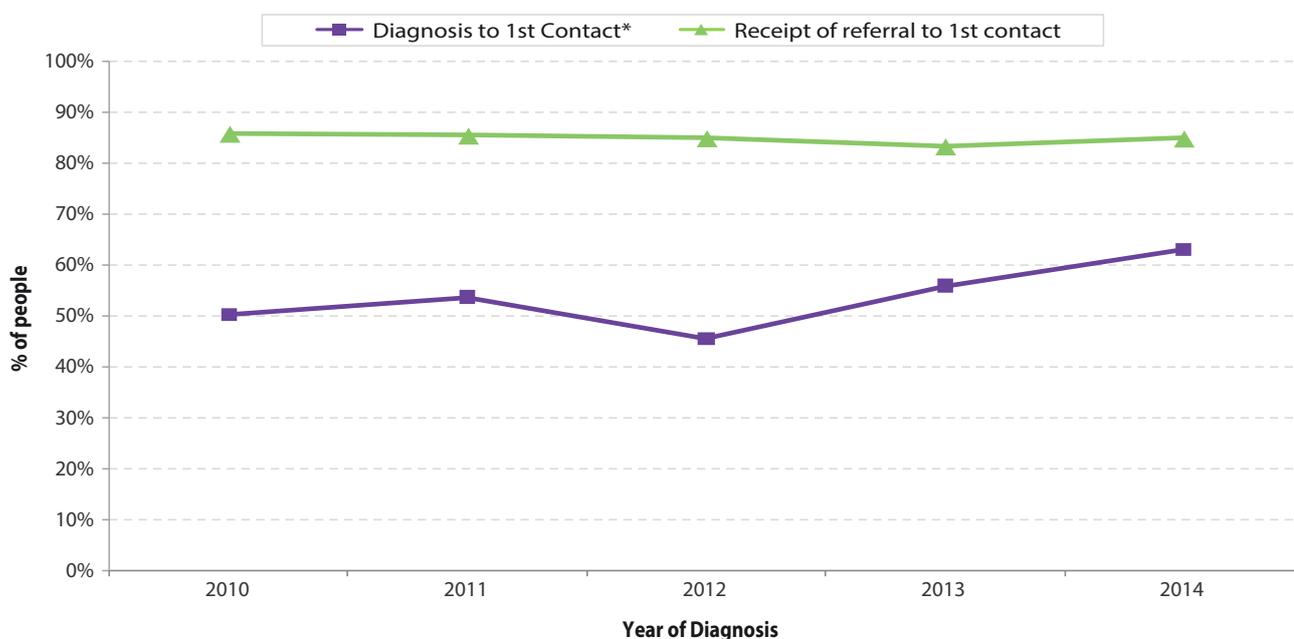
As noted previously data capture remains problematical and measures to improve this and to cross check the accuracy of both numbers reported and case verification will be a part of the work of the Register Steering Group in future years. It is of vital importance that the information contained within the Register is as complete as possible if the Register is to serve its purpose of informing service provision and service planning as well as forming a basis for crucial epidemiological research.

Some of the demographic information presented is already of significance especially the higher than anticipated average age at diagnosis and this may well have implications for service planning. A trend towards a geographical gradient from North to South will require further more detailed analysis.

The Register is however unique in capturing only those patients in whom the diagnosis of definite MS is as certain as can be and excluding patients with clinically isolated syndromes and “possible” MS. The purity of these data will provide an unparalleled opportunity for epidemiological research into the aetiology of the commonest cause of neurological disability in young people in Scotland.

Performance in Health Boards against HIS standard 15.2 is described and presented in charts 1 – 4 below.

**Chart 1** Percentage of people with a new diagnosis of MS contacted by a MS nurse within two weeks of confirmed diagnosis Vs percentage contacted within two weeks from receipt of referral, 2010-2014 data

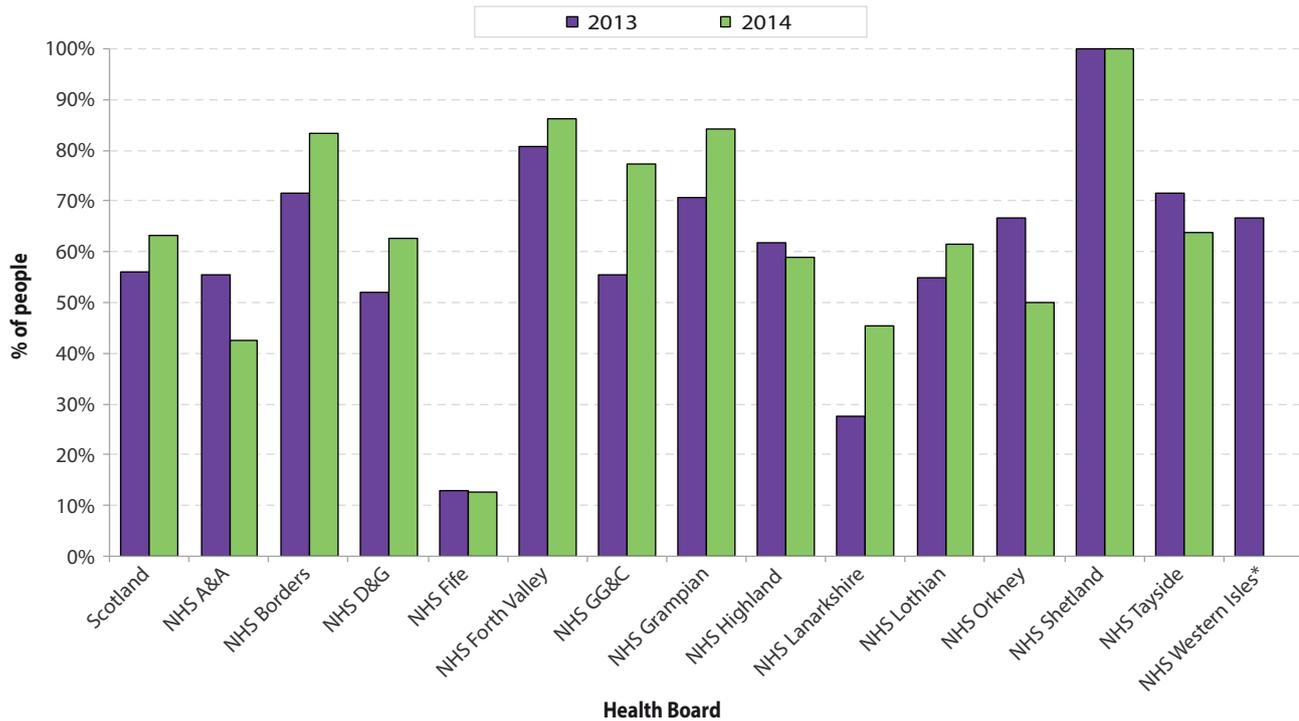


**Notes:**

- 1 Analysis above is calculated using cases for which contact with a MS Nurse Specialist was not declined. Cases for which contact was declined (Nbr = 26) have been excluded.
- 2 Two patients have been excluded from the calculation pertaining to the number of weeks between confirmed diagnosis and 1st contact (\*) as they both received a confirmed diagnosis from Consultant neurologists out with Scotland (Wales and Australia).
- 3 One patient has been excluded from the above analysis due to incomplete/missing date of confirmed diagnosis.

Chart 1 shows that there has been a continuing improvement since 2012 in overall percentage of newly diagnosed patients being contacted by MS nurses within the time frame specified by HIS standard 15.2. While the figure for those being contacted within the HIS specification once the MS nurse has received a referral from the diagnosing clinician has remained relatively constant over the five years covered by this report. The improving picture from the time of diagnosis while welcome, nevertheless falls well short of the specified standard and indicates a need for improved levels of communication between neurologists making the diagnosis and their nursing colleagues.

**Chart 2** Percentage of people with a new diagnosis of MS contacted by a MS nurse within two weeks of confirmed diagnosis, 2013 and 2014 data

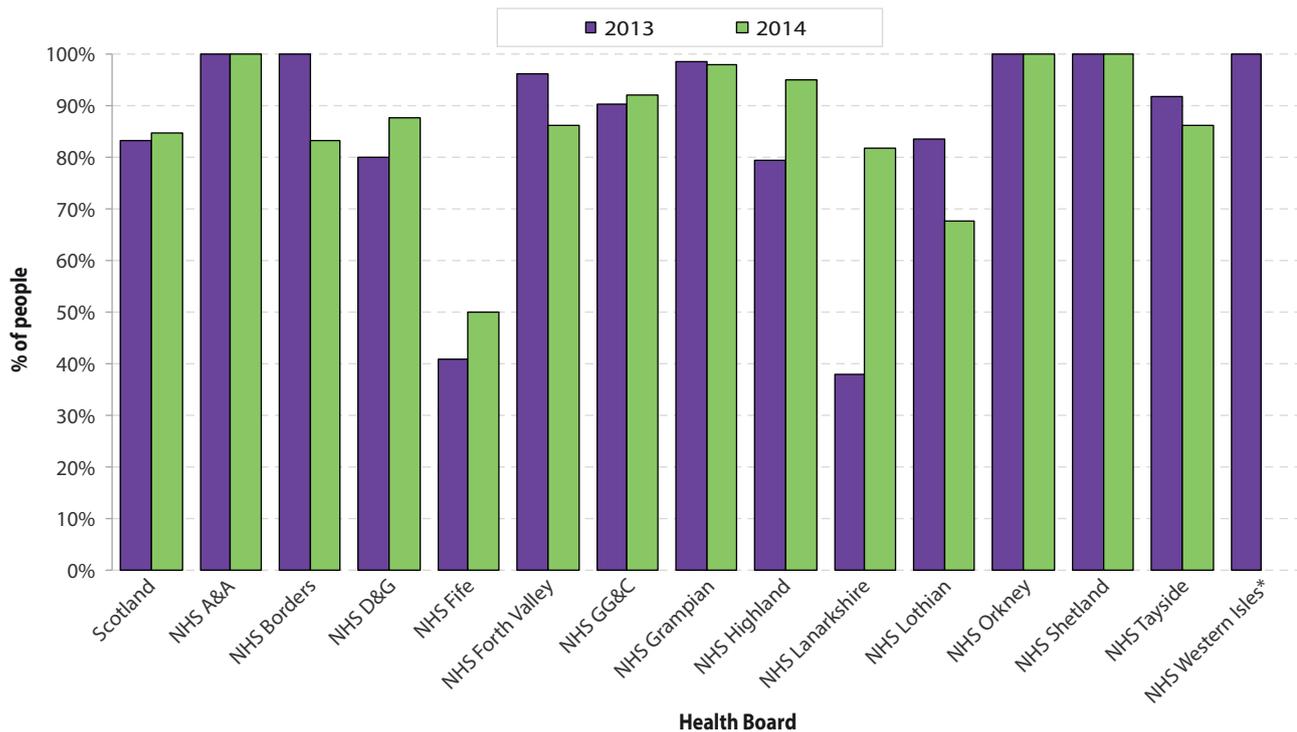


**Notes:**

- 1 Analysis above is calculated using cases for which contact with a MS Nurse Specialist was not declined. Cases for which contact was declined (Nbr = 3) have been excluded.
- 2 Analysis above is calculated using Health Board of residence. Consequently, the above may not be a true representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a different Health Board area than which they reside.
- 3 Health Boards indicated (\*) have declared that there have been no new diagnosis of MS in 2014.

Chart 2 highlights variations in performance at individual Health Board level. The majority of Health Boards have seen an improvement over the period 2013-2014. However three Health Board areas did not achieve even 50% of the required standard. NHS Ayrshire & Arran and NHS Lanarkshire patients are usually diagnosed either at the Institute of Neurological Science (INS) in Glasgow or by visiting neurologists (often general neurologists with specialist interests other than MS) from the INS undertaking clinics at local District General Hospitals (DGH). Communication to the local MS nurse is via clinic letter which may take up to six weeks or longer to arrive. The situation in NHS Lanarkshire has however shown a very significant improvement which reflects the appointment of a new MS nurse who has made strenuous efforts to improve the service and who has forged closer links with the visiting neurology staff from Glasgow. NHS Fife has particular logistical difficulties in that the MS specialist nursing service is based within the rehabilitation unit and the nurses do not work directly with the Consultant Neurologists.

**Chart 3** Percentage of people with a new diagnosis of MS contacted by a MS nurse within two weeks of receipt of referral, 2013 and 2014 data

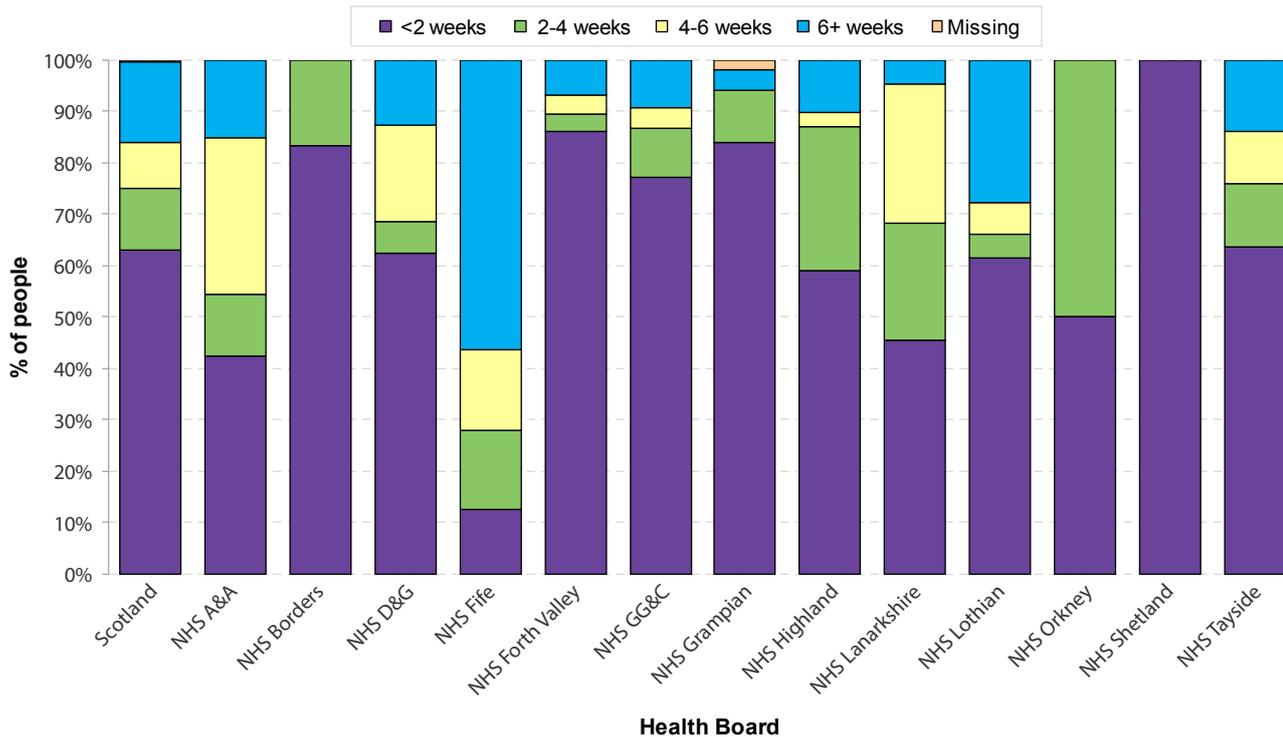


**Notes:**

- 1 Analysis above is calculated using cases for which contact with a MS Nurse Specialist was not declined. Cases for which contact was declined (Nbr = 3) have been excluded.
- 2 Analysis above is calculated using Health Board of residence. Consequently, the above may not be a true representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a different Health Board area than which they reside.
- 3 Health Boards indicated (\*) have declared that there have been no new diagnosis of MS in 2014.

Chart 3 gives a more realistic picture of the compliance with HIS standard 15.2 from the nursing perspective. Clearly it is unrealistic to measure nursing performance against the standard until the nurse is aware of a patient receiving a diagnosis. The mean of 85% of patients being contacted within two weeks of the nurse specialist receiving the referral has remained constant over the five years since the launch of data collection and the aspiration must be to bring this figure as close to 100% compliance as possible, several centres consistently achieve this goal and they are to be commended. Examining in more detail the reasons for success (logistical and organisational) in place at these particular centres to see if similar practices could be introduced at less well performing centres will be part of the Register's Steering Group remit going forward.

**Chart 4** Percentage of people newly diagnosed with MS in Scotland, by number of weeks from confirmed diagnosis to first contact with a MS nurse, 2014 data



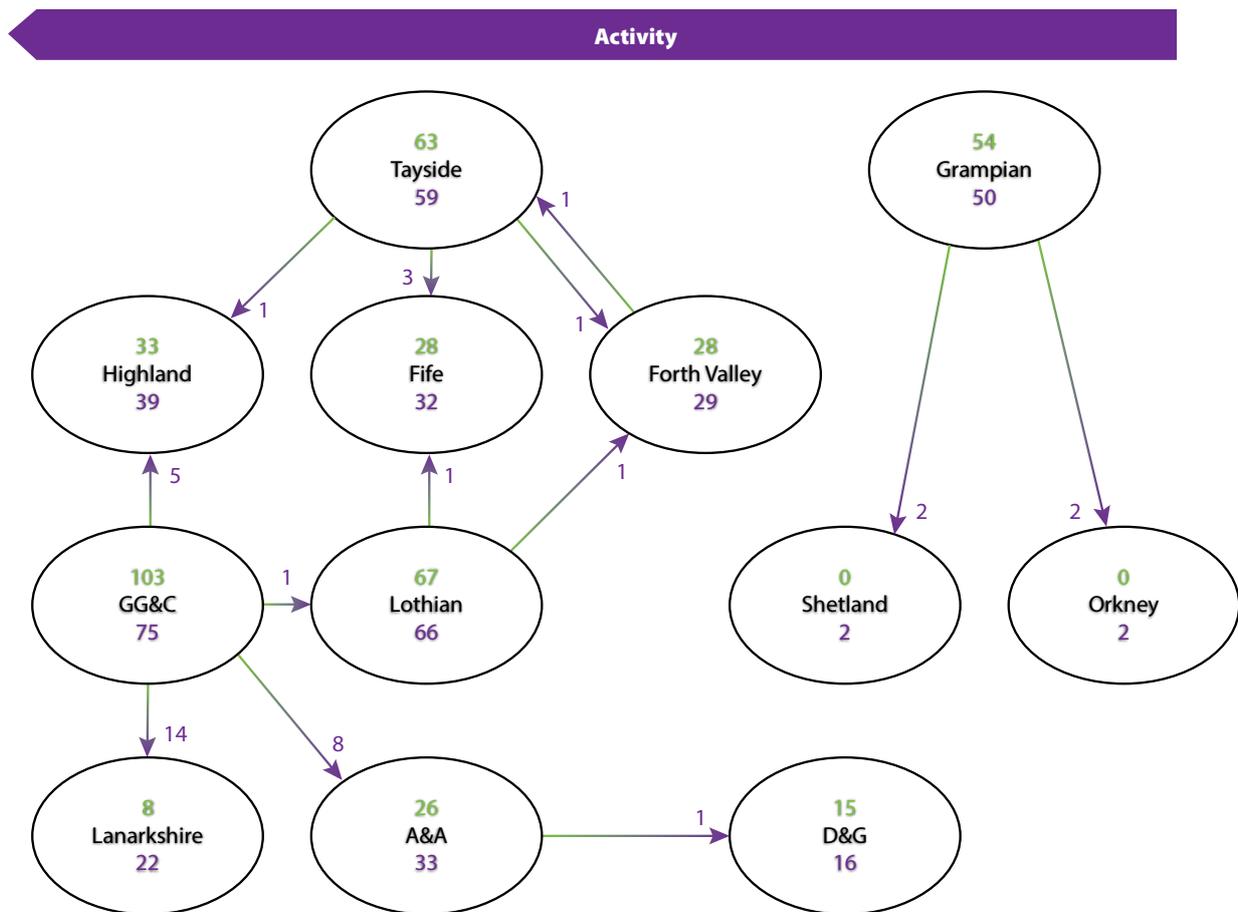
**Notes:**

- 1 Analysis above is calculated using cases for which contact with a MS Nurse Specialist was not declined. Cases for which contact was declined (Nbr = 2) have been excluded.
- 2 Analysis above is calculated using Health Board of residence. Consequently, the above may not be a true representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a different Health Board area than which they reside.
- 3 NHS Western Isles do not appear in the above as they have declared no new diagnosis of MS for 2014.

While there is an improving trend year on year from 2012 in relation to meeting HIS standard 15.2, chart 4 nonetheless still shows that some 16% (67 patients in total) of newly diagnosed patients with MS in Scotland waited longer than six weeks to be contacted by a MS nurse at a time when support and information can be of vital importance to the patient and their families.

The reasons for this situation arising may reflect inherent delays in communication between professionals but it is also pertinent to consider that overall numbers of MS Nurse Specialists practising throughout Scotland fall well below the MS Trust recommended level of 1 nurse per 358 MS patients.

**Figure 1** Number of patients newly diagnosed with MS in 2014 (Health Board where diagnosis received Vs Health Board of residency at time of diagnosis)



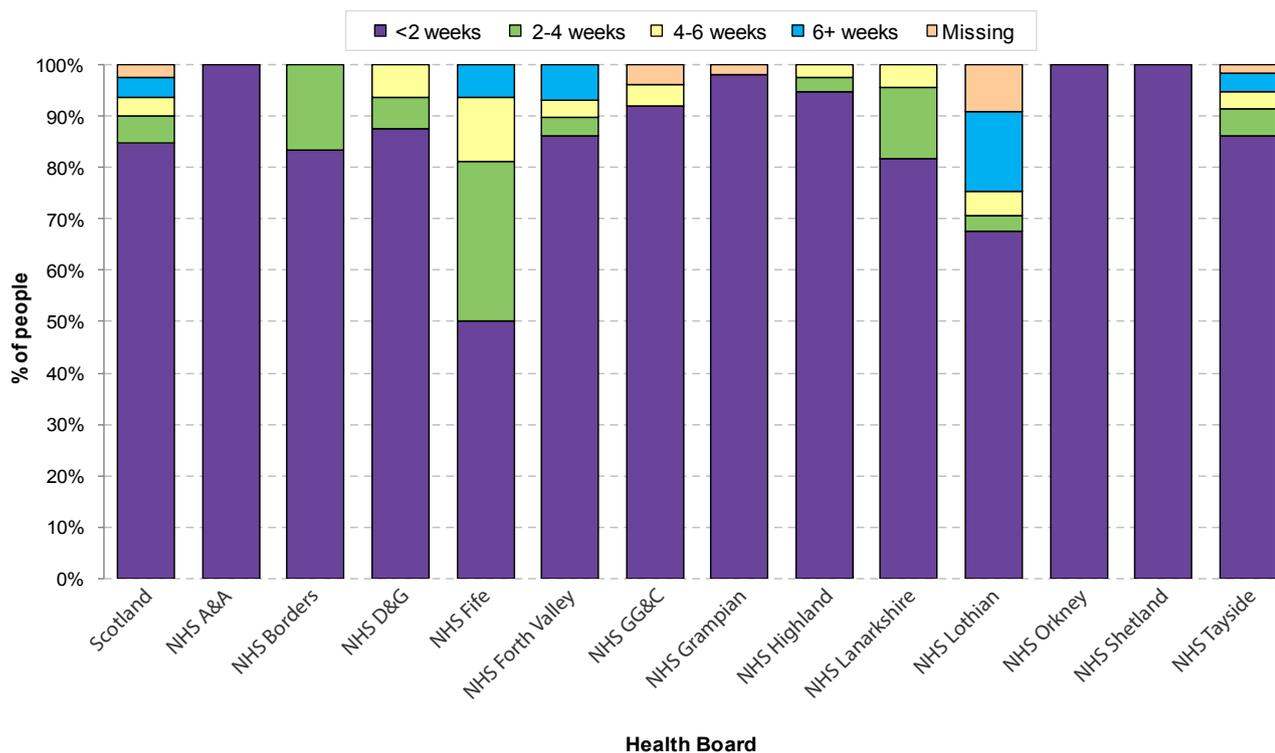
- Number of MS Incidence forms received from hospitals in each Health Board
- Number of MS patients recorded by Health Board of residency at time of diagnosis

**Notes:**

- 1 The purpose of Figure 1 is to illustrate cross border activity between hospitals and Health Boards.
- 2 NHS Borders does not appear in the above as there was no cross border activity between this Board area in 2014. Furthermore NHS Western Isles does not appear in the above as they have declared that there have been no new diagnosis of MS in 2014.
- 3 The above illustrates, for example, that 103 MS patient incidence forms were collected from participating hospitals under NHS Greater Glasgow & Clyde (GG&C) in 2014. 75 (73%) out of the 103 patients resided under the NHS GG&C Board area at the time of their confirmed diagnosis, 5 (5%) resided under the NHS Highland Board area at the time of their confirmed diagnosis, 14 (14%) resided under the NHS Lanarkshire Board area at the time of their confirmed diagnosis and 8 (8%) patients resided under the NHS Ayrshire & Arran Board area at the time of their confirmed diagnosis.  
Therefore:  $103 - 5 - 14 - 1 - 8 = 75$  (the number at the bottom of the NHS GG&C bubble).

### 3.22 Demographics

**Chart 5** Percentage of people newly diagnosed with MS in Scotland, by number of weeks from receipt of referral to first contact with a MS nurse, 2014 data

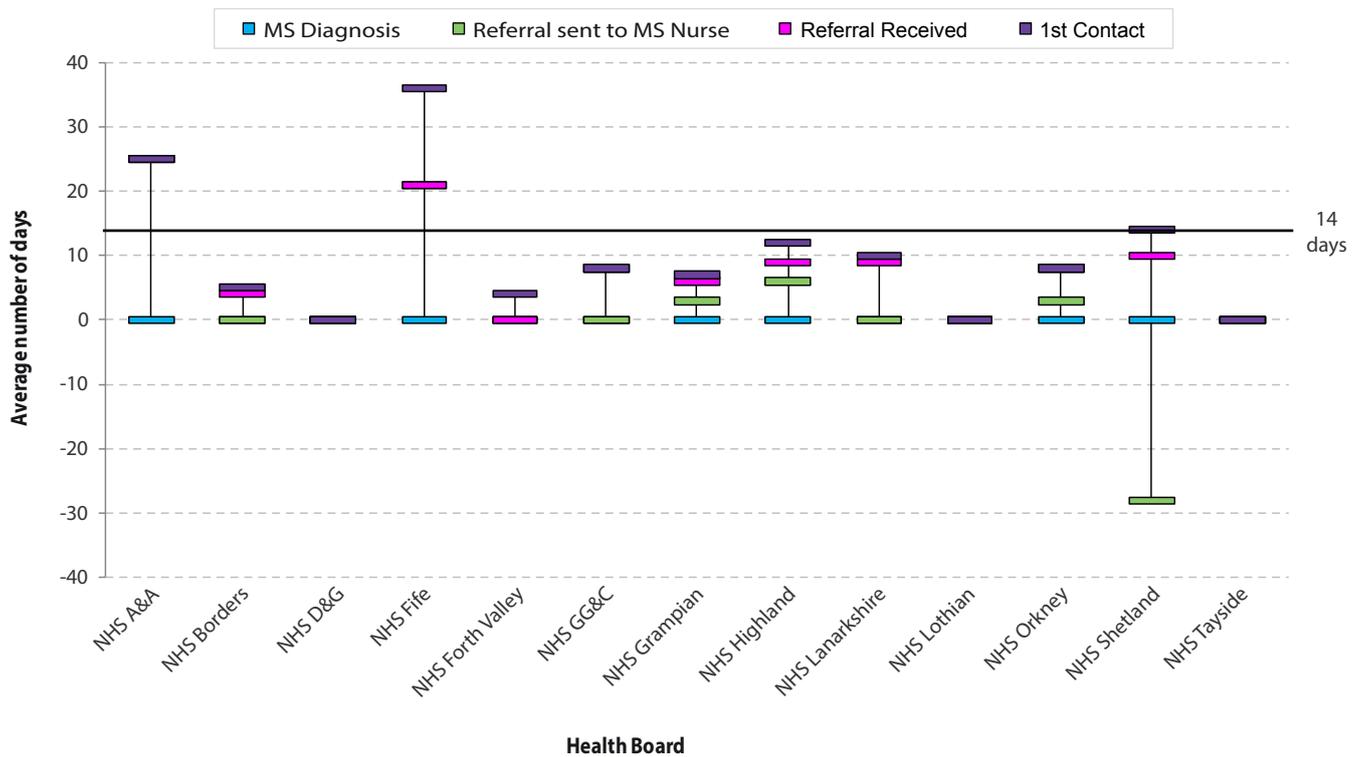


**Notes:**

- 1 Analysis above is calculated using cases for which contact with a MS Nurse Specialist was not declined. Cases for which contact was declined (Nbr = 2) have been excluded.
- 2 Analysis above is calculated using Health Board of residence. Consequently, the above may not be a true representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a different Health Board area than which they reside.
- 3 NHS Western Isles does not appear in the above as they have declared no new diagnosis of MS for 2014.

Chart 5 demonstrates that the MS nurses are clearly performing very well once they are informed of a diagnosis (despite high caseloads) with less than 5% of newly diagnosed patients waiting more than six weeks to be contacted after the MS nurse receives notification.

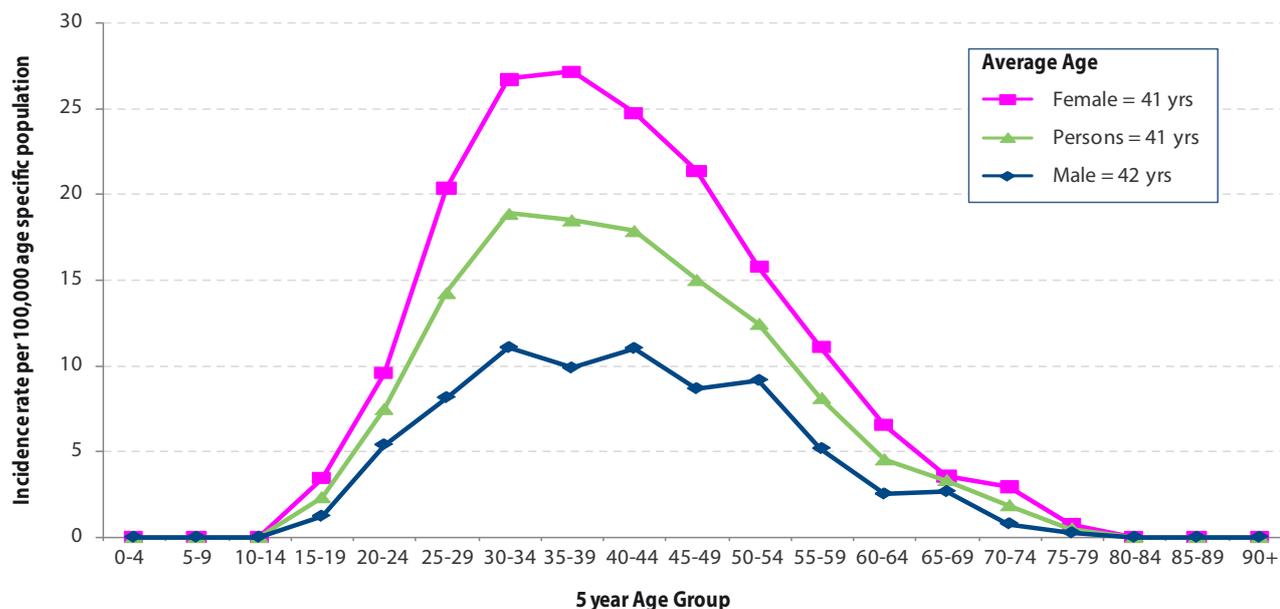
**Chart 6** Average number of days between each stage in the referral process from diagnosis to first contact by a MS nurse, **2014 data** (by Health Board, reporting on all patients with a new diagnosis of MS)



**Notes:**

- 1 Analysis above is calculated using cases for which contact with a MS nurse was neither declined or occurred prior to confirmed diagnosis. Cases for which contact was declined (Nbr = 2) and cases where contact occurred prior to diagnosis (Nbr = 38) have been excluded. Furthermore, the median number of days between each stage in the referral process has been used for the above analysis; as our data are largely skewed the median is more representative of the true average as it is less affected by outliers.
- 2 One patient has been excluded from the above analysis due to incomplete date of confirmed diagnosis being recorded. As a result calculations pertaining to the number of days between diagnosis and referral to MS nurses could not be carried out
- 3 Analysis above is calculated using Health Board of residence. Consequently, the above may not be a true representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a different Health Board area than which they reside.
- 4 NHS Western Isles does not appear in the above as they have declared no new diagnosis of MS for 2014.
- 5 Chart 6 illustrates, for example, that on average patients diagnosed with MS and residing under NHS Lanarkshire have their referral sent to a MS nurse on the same day they are given a confirmed diagnosis, hence why no blue icon can be seen. Furthermore, patients residing under NHS Lanarkshire usually have their referral letter received by a MS nurse within 9 days and contact is usually made within one day of receipt of referral.
- 6 As previously stated, NHS Fife has particular logistical difficulties which has resulted in a lower proportion of people meeting HIS standard 15.2 than anticipated. Clinicians and colleagues in the NHS Fife Board area are currently investigating ways to counter these difficulties - for further details see section 6, case study 1.

**Chart 7** Average annual age specific incidence of people newly diagnosed with MS in Scotland per 100,000 population, 2010-2014 data (by gender)



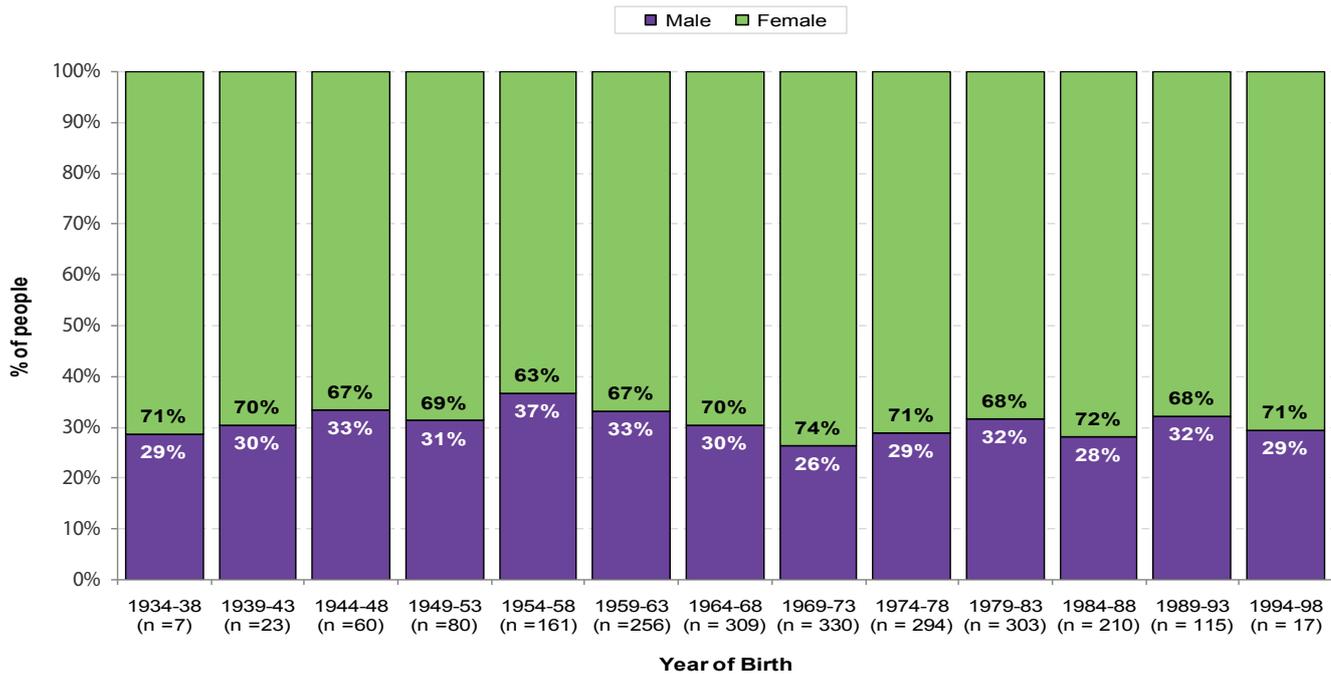
**Notes:**

- 1 Arithmetic mean of mid-year gender population estimates for 2010-2014 have been used for the above analysis, and the arithmetic mean incidence for each gender across this 5 year time period has been taken.
- 2 Arithmetic mean age for each gender is calculated using patients Date of Birth quoted at time of confirmed diagnosis.
- 3 Three males and five females were excluded from the above analysis as their date of confirmed MS diagnosis was unknown.

Chart 7 shows that the mean age at diagnosis for both men and women is higher than traditionally reported from previous studies including Rothwell and Charlton’s survey of Lothian (1998)<sup>5</sup> (mean age at diagnosis 34 years), however the figure is in keeping with more recent studies, for example Jick et al (2015)<sup>6</sup> reporting a mean age at diagnosis of 42 years between 1993 and 2006 from a UK wide survey based upon primary care data. Similarly Solano et al (2015)<sup>7</sup> reported mean age at diagnosis of 39 years in an Italian cohort.

The relatively high age for diagnosis reported from the Scottish Register may have significant implications for health and social services. Those diagnosed with MS at a later age tend to have more progressive types of the disease and taken with an increased association of co-morbidities with increasing age, the additional costs of both health and social care may be expected to be significant in the absence (so far) of any effective disease modifying therapy for progressive MS.

**Chart 8** Percentage of people newly diagnosed with MS in Scotland, 2010 – 2014 data (by gender and year of birth)



As noted earlier in this chapter the sex ratio of newly diagnosed patients with MS cumulatively over the five year period was 2.27:1 females to males. There was no evidence of any trend toward increasing numbers of females to males as can be seen in chart 8, contrasting with studies from other parts of the world which have suggested a significant shift in the female to male ratio Simpson et al (2012)<sup>3</sup> and Trajano et al (2013)<sup>4</sup> reporting such a trend in the UK and Northern Europe respectively.

**Table 3:** Number of people newly diagnosed with MS in Scotland, 2010-2014 data (by Health Board)

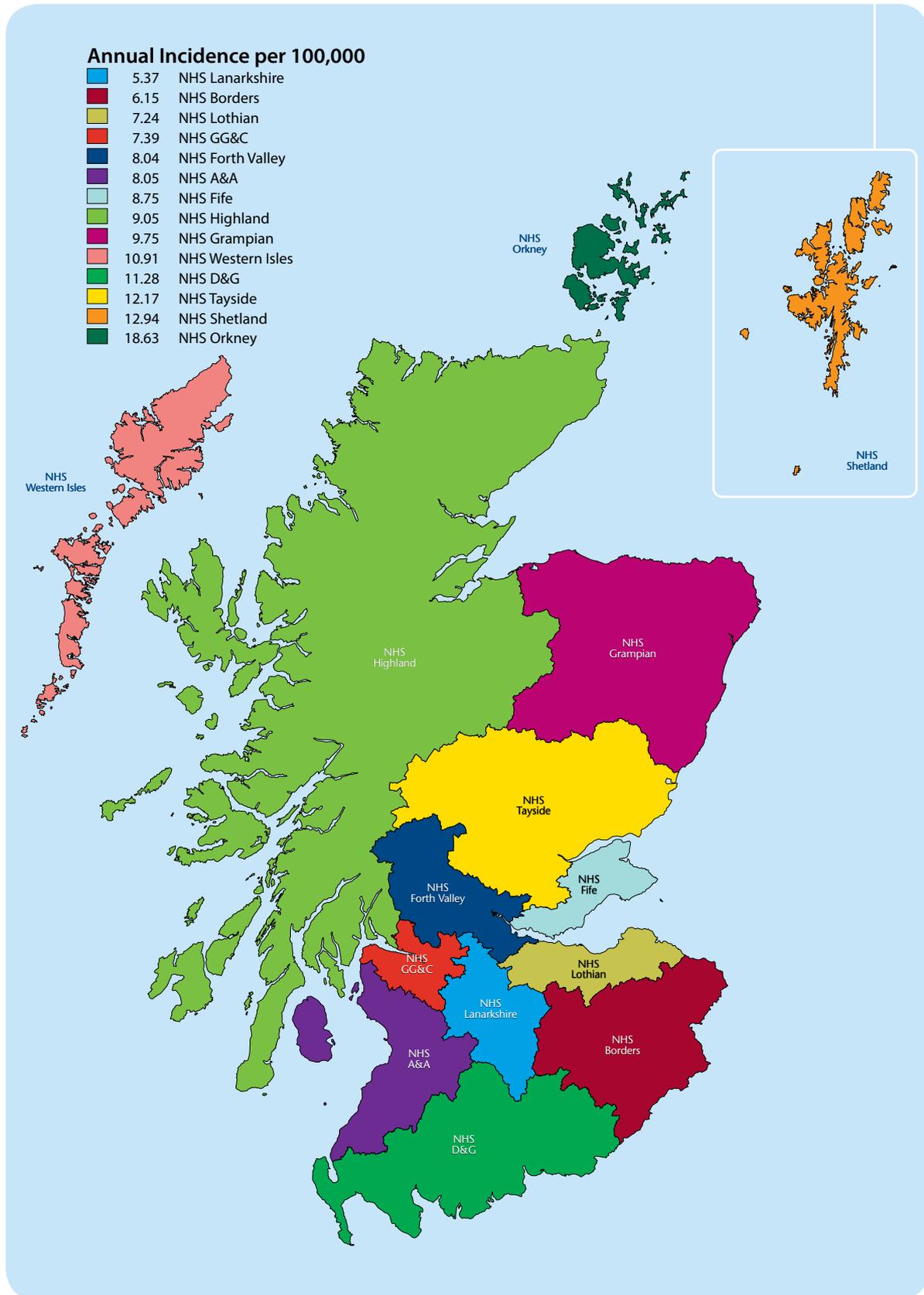
Health Board	Year of Diagnosis				
	2010	2011	2012	2013	2014
NHS Ayrshire & Arran	16	29	34	36	33
NHS Borders	8	7	7	7	6
NHS Dumfries & Galloway	12	16	15	25	16
NHS Fife	29	27	34	39	32
NHS Forth Valley	17	23	25	26	29
NHS Grampian	54	49	60	65	50
NHS Greater Glasgow & Clyde	95	83	82	83	75
NHS Highland	27	19	27	34	39
NHS Lanarkshire	48	30	46	29	22
NHS Lothian	60	54	50	73	*66
NHS Orkney	5	5	5	3	2
NHS Shetland	4	6	1**	1**	2**
NHS Tayside	42	42	56	50	59
NHS Western Isles	5	2	3	3	0
<b>Total</b>	<b>422</b>	<b>392</b>	<b>445</b>	<b>474</b>	<b>431</b>

**Notes:**

- 1 One patient, residing in NHS Lanarkshire Board area, did not have a year of confirmed diagnosis recorded and consequently has been removed from the above table.
- 2 2014 data for NHS Lothian (denoted \*) are incomplete due to data collection issues.
- 3 Data for NHS Shetland (denoted \*\*) are incomplete due to data collection issues.

Figures from individual Health Boards as presented in table 3 largely remained constant in terms of absolute numbers of new cases reported over the 5 year period 2010-2014. There are two significant exceptions to this with notable reductions in absolute numbers of new cases reported from NHS Greater Glasgow and Clyde and NHS Lanarkshire Health Boards. The constancy of the numbers reported by the majority of Health Boards is reassuring in relation to adequacy of data capture but further investigation is required around the figures reported from NHS Greater Glasgow and Clyde and NHS Lanarkshire.

**Figure 2** Average annual incidence of people newly diagnosed with MS per 100,000 population, 2010-2014 data (by Health Board)



**Notes:**

- 1 The arithmetic mean population estimates across the 5 year time period have been used in the above analysis and are calculated using mid-year population figures from the General Register Office for Scotland, estimated for the 30th of June each year.
- 2 The average incidence of MS across the 5 year time period is calculated using Health Board of residence.

Interestingly the map presented as figure 2 tends to illustrate a North to South geographical gradient of incidence within Scotland, something that has been traditionally held to be the case in more global descriptions of worldwide patterns of MS incidence and prevalence with both rising with increasing distance from the equator.

Given the relatively small total numbers involved however this should be interpreted with caution. It does however raise interesting questions for future research if this trend is shown to be continuing in future years. Are there for example particular environmental factors responsible? Is there more genetic homogeneity in Northern communities? Could it be that there is more awareness of early MS symptomatology in smaller more closely knit communities?

NHS Dumfries and Galloway also seems to be an exception to the overall trend, small numbers from one of the smaller Health Boards may of course distort the statistics but nonetheless the apparent anomaly merits further investigation.

## 4. Primary care data to determine prevalence

### 4.1 NHS Ayrshire & Arran

Two primary care based surveys of the epidemiology of MS in NHS Ayrshire & Arran have been undertaken. The original investigation being undertaken in 2008 with a 5 year follow up study in 2013.

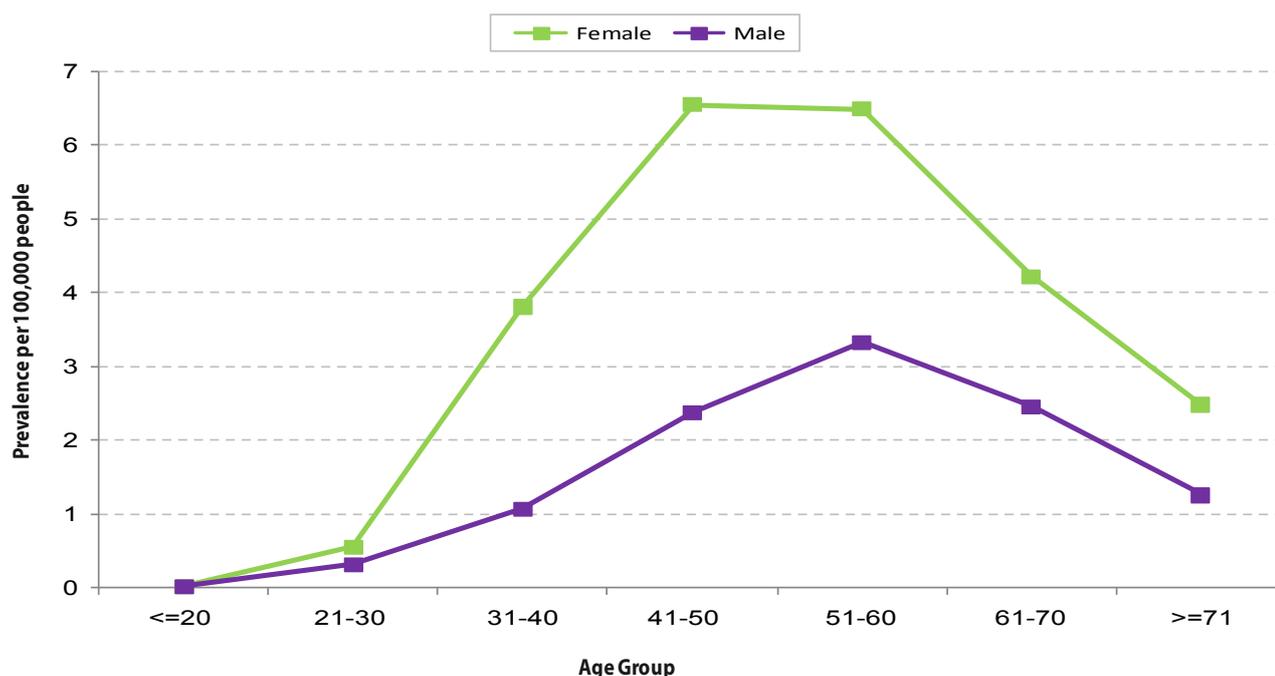
The methodology used was the same for both surveys and was developed with the assistance of the clinical effectiveness department of the Health Board. A software extraction tool was developed to identify MS data from each GP practice list using READ codes. All 59 practices within NHS Ayrshire & Arran agreed to participate.

The following information was extracted:

- Practice population;
- Practice locality;
- Total patients with MS;
- Sex of patients with MS;
- Age range of patients with MS;
- Age in years of patients with MS;
- Diagnosis date of patients with MS; and
- Practice male and female populations

Total prevalence of MS in the 2008 data was 235 per 100,000 approximately 25% higher than that reported by Rothwell and Charlton from their Lothian and Borders study (1998)<sup>5</sup>. Female to male ratio was 2.5:1 (similar to that in the present report of the SMSR).

**Chart 9** Prevalence by age and sex band in NHS Ayrshire & Arran, 2008 data.



**Note:**

1 Data above have been submitted by colleagues in NHS Ayrshire & Arran. As a result, data behind prevalence calculations are not available.

Information on year of diagnosis was analysed for the five year period 2002-2007 to inform incident rates and is presented in chart 9. There was a mean of 46 new cases per year of MS recorded within GP data for this period translating to a mean incidence rate of 12.2 per 100,000 almost identical to the figure reported by Rothwell and Charlton in Lothian (1998)<sup>5</sup>. If this figure were extrapolated to Scotland as a whole there would be expected to be approximately 650 new cases of MS per year, significantly higher than is reported by the SMSR data.

Overall prevalence rates reported from the follow up survey in 2013 revealed a rate of 269 per 100,000 a 14% increase in prevalence over the previous five years.

Incidence rates however over this period fell to 8.5 per 100,000 which is close to the overall figure obtained from SMSR over the period 2010-2014 and which may lend weight to the view that overall incidence rates may be falling.

A wider study of primary care data from different Scottish regions would be helpful in providing some validation of the SMSR data.

**Dr Paul Mattison,**  
NHS Ayrshire & Arran

## 4.2 NHS Lanarkshire

As has been discussed already the data we have and present within this report are collected from a service perspective. By this I mean that it comes from MS services principally from neurology departments where a diagnosis is made or MS nurse associated services where patients are known about. We do not know how far this database reflects the totality of patients with MS within Scotland, perhaps whose diagnosis was many years ago prior to the commencement of the Register and are not in continuing contact with any services.

The project in NHS Lanarkshire is to determine the prevalence from GP data. This should be easy to do. Search on the diagnosis and get the numbers. Reality, as ever, is somewhat different.

- GP data are not quality controlled by any organisation so it may not be complete or recorded consistently;
- Diagnostic data may be incomplete if different codes were used. These may be using a different name (optic neuritis) or an error (like Family History of MS rather than MS);
- Date of diagnosis may be accurate or may be the date that the patient joined the practice; and
- GPs are their own data controllers so must be satisfied that release of this information to us within Lanarkshire will not result in release of patient identifiable information to the public arena.

Given these cautions we are seeking to determine the prevalence of MS across Lanarkshire GP systems and compare it with the MS Register data. A search and associated instructions has been sent out to GP Practice Managers and the data are being returned to the primary care office where it will be amalgamated into a single database before having CHI numbers and some location data removed.

The process is longer than expected! Data are now flowing and will be included in the next report.

**Dr Chris Mackintosh,**  
NHS Lanarkshire

## 5. Use of SMSR data in research

Utilisation of data within the Scottish MS Register is thought to be a vital aspect of our understanding the impact MS has in the nation. The accumulation of incident data of such a complete nature should lend itself to answering a number of scientific questions. To that end within the SMSR Steering Group a dedicated Research Sub-group has been established this year.

### 5.1 The SMSR Research Sub-group

The group has a representation from throughout the country with neurologists, public health physician/ epidemiologist and information analysts.

The objectives of the group have been agreed as:

- To review proposals for access to SMSR data for consideration for research;
- To explore research avenues which the SMSR Research Sub-group could undertake;
- To co-ordinate academic activity using Scottish MS Register data;
- To undertake research projects on behalf of the SMSR leading to publication; and
- To deliver poster/ podium presentations sharing and promoting the work of the SMSR.

It has been agreed that in order for decisions to be made the chair or nominated deputy should be present along with three other representatives, including at least one SMSR central team representative at the relevant meetings.

The current membership of the group is:

Title	Current holder
Chair	Dr Jonathan O’Riordan
SMSR Chair	Dr Belinda Weller (deputy chair)
SMSR National Coordinator	Hazel Dodds
NSS/ PHI	Amanda Gilmour Martin O’Neill Dr Hester Ward
Ordinary members	Dr Paul Mattison Dr James Overell

It was agreed that additional members may be co-opted with members approval if specific expertise is required.

Responsibilities of the group include:

- i) Actively participating in and directing the development of SMSR research;
- ii) Engagement with other academic structures on behalf of the group;
- iii) Providing expertise for local interest in SMSR research;
- iv) Focus for all research activity within SMSR locally;
- v) Authorise use of SMSR data for Information Requests;
- vi) Sourcing of funding to facilitate SMSR research; and
- vii) Assistance with epidemiological and statistical advice.

The group will meet at least 3 times per year.

## 5.2 Current projects under consideration

A number of projects are currently under consideration and being progressed by the group:

### 1 Prescribing data links.

This aims to link a number of databases and evaluate prescribing data among MS patients on the Register. The group is looking at linking prescribing in primary and secondary care, evaluating trends and outcomes.

Dr Kerr Grieve has been appointed as a Research Fellow at the University of Dundee under supervision of Professor Tom MacDonald and Dr Jonathan O’Riordan. This is a 3 year post with the aim of obtaining a PhD.

Dr Grieve will work in collaboration with the SMSR Research Sub-group and as part of his work he hopes to look at the clinical outcomes for patients on the Register and link prescribing practices in primary and secondary care.

### 2 National Epidemiological Trends

Dr James McDonald, Edinburgh University as part of his online MSc was planning to look at the epidemiological trends of MS over time, see if there is any association with latitude, any incident hot spots and any association with deprivation.

With that in mind he will format a proposal for submission to Edinburgh University and this would then be reviewed by the SMSR Research Sub-group and it is hoped that this could also be a collaborative piece of work going forward.

For anyone interested in accessing the information held within the Scottish MS Register information regarding the process and governance arrangements for requesting data from the SMSR can be found at <http://www.msr.scot.nhs.uk/Research/Main.html>.

All requestors of data (non-audit personnel) should complete an ‘Information Request Form’ also available at <http://www.msr.scot.nhs.uk/Research/Main.html> and email it to [NSS.isd-ScotHealthAudits@nhs.net](mailto:NSS.isd-ScotHealthAudits@nhs.net).

## 6. Use of data to drive improvement in delivery of services/ care

### Case study 1: NHS Fife

#### **How the MS Register data were used to improve the Newly Diagnosed Pathway in NHS Fife.**

The MS Clinical Nurse Specialist is a member of the multi-disciplinary team at the Fife Rehabilitation Service (FRS), Cameron Hospital, Windygates. The Neurology Service is based at 2 acute hospitals, 7 and 22 miles away. The diagnostic phase is managed by the Neurology Service. Following diagnosis, patients can be referred to FRS for ongoing information, support and symptom management by the diagnosing Neurologist. Currently the MS nurse completes the MS Register dataset form once she receives the referral.

The MS nurse presented data from the 2012 SMSR Report to her colleagues at FRS to highlight areas specific to the journey that required to be addressed by FRS. This included the time delay between the date when the referral was received by the MS Team and the time to referral being received by the MS nurse.

The reason for this delay was due to all referrals receiving a medical assessment prior to seeing a member of the team. This was reviewed and as a service it was proposed that patients, where appropriate could be referred straight to the team. This resulted in a significant reduction in waiting time for this part of the journey.

All MS referrals are now triaged at the weekly out-patient meeting and can be directed to the MS nurse where appropriate prior to medical review. A further redesign took place in April 2015 which allowed for all newly diagnosed patients to be fast tracked to the MS nurse for contact within 10 days, instead of a medical assessment.

It is expected that this improvement will be reflected in next year's data for the 2016 SMSR National Report.

The next stage is to improve the time delay for when an individual receives a diagnosis in Fife by a Neurologist and the referral being received by the MS nurse within FRS. The SMSR Report 2014 has been discussed with key staff in NHS Fife and questions have been asked as to why NHS Fife is currently not meeting HIS Standard 15 for the complete journey.

**Debbie McCallion**  
MS Nurse, NHS Fife

### Case study 2: NHS Greater Glasgow and Clyde

#### **How we reduced the waiting time for patients to have face to face appointment with the MS Nurse Specialist.**

NHS Greater Glasgow and Clyde regional MS Nurse Service has in the past met the HIS standard 15.2: 'Contact with an MS Clinical Nurse Specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days.' by sending contact details to the patient on receipt of a referral from their Consultant Neurologist.

Although this fulfilled the standard it often took up to 3 months before a face to face clinic appointment occurred between the patient and the MS nurse. During this first clinic appointment

plans, made by the Consultant Neurologist, for disease modifying therapy (DMT) were finalised with the patient and treatment was organised.

The MS nurse team realised this added wait was stressful for patients and there was also a risk that patients would deteriorate while waiting to have their treatment started. After discussion amongst the MS nurse team, a solution to reduce the waiting time was found.

It was recognised that more clinics with the original template would have quickly been filled with return patients and the problem would only have been temporarily resolved. Therefore with the help of the Clinical Services Manager, the MS nurse team developed a different clinic template which is exclusively used for patients starting DMT. No routine or return patients can be booked into the slots. It provides us with four, forty five minute appointments every week that we can access quickly allowing us to see patients face to face and help them understand the DMT choices available to them.

Following this change we are now seeing patients within 3 weeks, rather than the potential 3 months wait of the past.

**Dr Stewart Webb**  
NHS GG&C

## 7. Patient Reference Group

Since John Sutherland's work at the Raigmore Hospital in the early 1950s, 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 in percentage terms being in the Northern Isles. These assumptions, however, were based upon small studies of discrete parts of the nation and it was only in 2005 with the initiative of the then Director of the MS Society Scotland, Mark Hazelwood, that the Scottish MS Register was instigated and this national collection of data formulated. From the outset, Hazelwood and the project manager, Claire Kennett, wished to involve the views of people with MS (PwMS) and a representative group of patients was established. This has always fed its opinions and concerns into the Register and we are confident that this unique Scottish endeavour is providing information which is being used to improve the quality of life of people with MS in Scotland.

When the Register commenced, we knew that it would take at least five years before we could rely upon any of the trends that the collection of these data were revealing and having now reached that point we decided to expand the Patient Reference Group through incorporating patients whose information had contributed to the Register as they had been diagnosed since the start of the Register.

The Register's data mean we can now more reliably ascertain where PwMS are, what clinical and other support is required, and whether services are meeting published national standards. The Register was established to develop a 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 continues 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 are 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 patient pathway. For example, the MS Nurse Specialists have highlighted to clinical staff where delays are occurring and highlighted that the earlier they receive a referral, the sooner the support from the MS team can be initiated. This improvement continues with 63% of newly diagnosed patients being contacted within two weeks of their diagnosis — this continues to fall well short of the HIS standard 15.2 described earlier in this report, but is an improvement on an earlier figure of only 50%. Once the MS Nurse Specialist receives the referral, nearly all patients are then contacted within two weeks. Administrative procedural delays in the reporting system are still evident in a number of cases and it is the information that the Register gathers that identifies such problems and leads to the necessary improvements that are then experienced by the 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.

The SMSR Patient Reference Group continue to contribute to the ongoing development of the SMSR and were recently asked to review the Patient Information Leaflet provided to patients who are being added to the Register.

Once this report is published it is planned to develop a summarised version suitable for patients/ carers and the wider public in the form of a leaflet that will be available online and at clinics across the country. The SMSR Patient Reference Group will review this report and discuss the content of the proposed leaflet at their next meeting in November 2015 contributing to its development and publishing.

**Dr. George Mowat-Brown**  
Chair MS Patient Representative Group

## 8. The patients' perspective

"I was diagnosed with MS in 1997. At that time I was attending hospital as an outpatient in respect of a back complaint. An MRI scan revealed that I had MS. A consultant neurologist, who I had never met, informed me that the scan had revealed that I had MS. I was offered no further information at the time about the condition and was offered no support.

In my attempt to learn more about the condition I contacted the MS Society in Scotland. The Society provided me with the information I required at that time.

Over the past few years I have observed a dramatic and very effective change in the services now provided by my Health Board. This has principally been brought about by the appointment of MS specialist nurses in Tayside who have been of considerable assistance, help and support to me. I have also had tremendous support and guidance from my neurologist who I see annually."

**Bryan**  
Tayside

"I live in a rural part of Argyll, I was diagnosed 8 years ago in November at the age of 25, I have to say it was the most petrifying time of my life. I was on a stroke ward at the Southern General Hospital (SGH) for over a month while they did tests. To have the diagnosis of MS was such a HUGE relief compared to the possibility of a brain tumour or stroke! After diagnosis me and my family were given barely no support or advice. We had to hunt it out ourselves.

I will say though that the support from GPs etc .was there even in the early days if needed but it was so difficult to know what to ask! There wasn't the information about at that time for us to browse, it was only if we had specific questions!

In the last year I have had a few dealings with our new MS nurse, she's a lovely lady! We are so lucky to have her in this area now! Before she arrived, we had to phone one of the nurses at SGH or see the nurse down there once a year! Information is also now also more readily available."

**Patient with MS**  
Highland

"I was diagnosed with MS 19th April 2013. I had been tested for meningitis/ MS in 1995 (lumbar puncture, x-ray, bloods etc.) the result being noted as trapped nerves in neck and arms. I lived and worked with these painful symptoms (neuropathic pain) which occurred every couple of years (relapse), along with 12 weeks query labyrinthitis. There was no follow up and no MRI scan.

Initially I went to my GP with a heavy feeling in my thigh, January 23rd 2013. I had bloods done, returned 1st February, and referred to Neurologist as bloods were negative, GP queried MS. I saw the Neurologist 1st March, which I thought really quick all within a month! He ordered MRI, was seen by Neurologist 19th April, given definitive diagnoses of MS. The Neurologist discussed DMT (injections) therapy, and asked me to contact MS nurse regarding further information about treatments. Phoned & was seen by MS nurse 13th May, 3wks & 3 days after Neurologist.

Saw MS nurse again twice in May. I had a lot to deal with, my own diagnosis, my mum was in hospital, I was off sick from work, treatment decisions to make and going through a relapse. Having the support of my MS nurse was invaluable, you don't know what to think, it's all new, alongside all this I saw my GP for lines off work, and to check how I was.

The MS nurse referred me to the Rehabilitation Consultant, who I saw on 20th June, physiotherapy for my leg three times in July and also saw the OT three times in July. I had a banister fitted to help me go upstairs.

When I look back ,I can't believe the people involved to help me through my initial diagnosis, and the support that I was given, I don't know how I would have been without there help. I was told by them all to contact them if there was anything I needed to discuss (anytime). This was the Rehabilitation Unit at Cameron Hospital, Fife.

From August, I saw the MS nurse, GP, OT and physio regularly (for my leg) and rehabilitation doctor just to see how things were going. I was also referred to the Neuropathic doctor for query carpal tunnel and physio for bladder issues.

Up to the present day, I see the MS nurse every few months, she says just to email or phone if I need anything. I have seen physio regularly & just to phone them also, I can refer myself to them at any time.....fabulous service. I don't feel alone through this journey, I don't know what it was like years ago for services, but today, for me..... I feel very lucky to receive this service."

C Anderson  
Fife

"This is my story so far, there have been lots of ups and downs. I was diagnosed with MS around 7/8 years ago. I had to push very hard for a diagnosis and had some difficulties with the clinician I saw in the first instance in that he was unable to answer my questions and in my opinion was not supportive and lacked an appropriate bedside manner. The doctor did call the next day and acknowledged our conversation hadn't gone well. At this point I was offered a lumbar puncture to hopefully confirm my diagnosis MS. I didn't have a good experience during the lumbar puncture procedure as unfortunately the first attempt failed and the procedure required to be re-done.

I found a lack of appropriate support and resources was an issue in the early days, for example, I was given a badly photocopied A5 booklet about MS advising me to use a rucksack when I went shopping, use ready meals, get someone else to hang out your washing etc. - it was awful and gave me no kind of encouragement, hope or guidance for the future. There also seemed to be a lack of resources to help support families and friends in 'how to do MS' and be a support to the patient. In the last few years I have picked up resources from the MS Therapy Centre which are more practical about some of the problems you might encounter or need guidance on. The new Anne Rowling Centre is a new/ developing resource for neurological conditions and has a lot of booklets available on MS which are very helpful.

In relation to service provision - I always had to be seen at the MS Clinic at the Western and had appointments with a great MS physio - she was fantastic but it was always hard to get an appointment with her as she was the one and only MS physio in the area! When she subsequently left she was never replaced and that resource has been badly missed since.

A lack of communication has been an issue also, for example travelling from the South side of Edinburgh to the Western for appointments was always a struggle for me and got harder and harder to do. By chance I found out about a MS clinic at the RIE. Thankfully I would now be seen at the Friday afternoon MS Clinic at Little France for all of my appointments but would have to be seen by a different consultant, which was a shame. Unfortunately in 2013 my appointments changed to a morning clinic. I asked if there were afternoon appointments but was curtly told that there was no longer an afternoon clinic. I cancelled the appointment and spoke to my MS nurse and was told they hoped to have an afternoon clinic at some point at Anne Rowling but didn't know when. Mornings continue to be worse for me and though the afternoon clinic was much better I now have to see my consultant in the morning as there is such a demand for the use of rooms. This unfortunately makes

life difficult and doesn't help me, the patient! - so that continues to be a problem area for me and there is often a problem with getting patient transport for appointments.

I eventually was seen at the beginning of 2014 by a different consultant (another change) but this was only to go over my notes etc. and I was asked to make another appointment for 5/ 6 months time - to go back in the summer to discuss my tablets etc. I went back in the summer expecting a full examination as I was a new patient to him. This didn't happen which I found odd. I also mentioned some speech problems I was having (I now realised that this could be a symptom of MS, albeit I didn't know too much about it). He totally dismissed my comments and question and told me it was probably the hot weather. I was not convinced by this, but would wait to see what his consultation notes said about me, which he promised to post out to me and my GP. The notes came with no reference to my comments/ question re my speech - I was alarmed and not convinced by his dismissal! I phoned my GP to come and visit me about health issues and I asked her to get me a second opinion by a different MS consultant for a full MOT and I wanted to be seen by a speech therapist. Both happened and my speech problems were confirmed by the speech therapist and consultant. I am pleased to say I then had several helpful sessions with the speech and language therapist.

I am interested in the effects of vitamin D on MS and over the years I have asked for my blood to be tested for this and always told 'no' by consultants and GP's. In early 2014 I asked my GP 'again' and this time he said 'he would agree to it now'! My GP prescribed a daily vitamin D supplement. I also asked him if I needed to be tested again after a few months of taking the tablet but was told no. I was told it is an expensive test to do and it can only be done once a year! I have recently submitted blood for a vitamin D test for this year and await my results to compare with last year's test. I think this process is long and not efficient or helpful to 'the patient' and seems such a battle to do."

Patient  
Lothian

"I am a 58 year old woman who has been living with MS for 24 years. I was diagnosed in 1991. I was 34 years old, and at the time, working in a GP Practice. I had previously been a nursing student, but I had found myself struggling with the demands of nursing and family, and in hindsight, the first symptoms of MS, and decided to leave for an offer of part-time work.

I was diagnosed very quickly after presenting for the first time to my own GP. Over the course of one weekend, I had become increasingly unable to walk. I felt heaviness in my legs, had trouble walking, and in a matter of a few hours both feet and legs were completely numb, making movement without support impossible.

I visited my GP on the Monday. He was visibly concerned, but suggested it might be a viral infection, which would improve spontaneously. He asked that I return the following day if there was no improvement. When I returned on the Tuesday, markedly worse, he immediately phoned the hospital asking that I be seen as a matter of urgency, as he thought I might have Guillaine-Barré Syndrome.

I was admitted to hospital, had a lumbar puncture, spent two days lying flat to recover, then a further few days in the hospital before being discharged home. I have little recollection of those first few weeks, other than being relieved that it hadn't turned out to be Guillaine-Barré. I was impatient for my return to hospital for the results of the lumbar puncture, but I don't recall it taking more than a few weeks, and I was noticeably improving day by day.

I feel that I was lucky to have been diagnosed so promptly and honestly. I knew patients who waited many years to be told of their diagnosis.

Post diagnosis, my care was managed entirely by my GP for the first few years. I don't recall any referral to Neurology, and there was no MS support team at that time. To my recollection, I was first referred to a Neurologist many years later (around 2006) to discuss the option of DMT treatment. By then, I was seeing the local Rehabilitation team and the MS nurses, who had been in post since around 1996, and I felt more supported.

In the early years post-diagnosis I had 2/3 relapses per year mainly affecting mobility. I had lost my job (pre date of diagnosis), studied to be a Counsellor, and worked as a charity volunteer until fairly recently.

I have been a Support Volunteer with the MS Society for many years. I am delighted to see that the experience around diagnosis has become much more open and supportive as new treatments become available. I remain concerned however, that the lack of staff and resources means that some MS patients are still not being seen even as often as once per year."

Liz  
Fife

## 9. The MS specialist nurses' perspective

"I came into post in January 2002. This was a brand new post for NHS Highland. There was no MRI scanner in Inverness. Neurologists came from Aberdeen to do clinics. Patients needing investigations (MRI scan) had to travel to Aberdeen. The MS Society, MS Trust and local branches were very supportive. The role was working with the Rehabilitation Consultant working mainly with people with moderate to severe MS. At the end of my first year I had completed 488 home visits and seen 165 patients in hospital. I had made 386 phone calls and received 965 calls. It was thought there might be about 500 people with MS in Highland.

Gradually over the next few years we got our own Neurologist (General Neurologist) and our own MRI scanner. In 2004 I took over the role of monitoring Disease Modifying Therapies (DMT). In 2005 I got a secretary for 16hrs a week. I managed to attend education and study days along with Scottish MS nurses meetings often in the early years. In 2006 I started an annual newly diagnosed information day. By now my role was changing. I was seeing more people newly diagnosed and was more involved with the medications. In 2007 I was doing 18 clinics a year in Inverness alone. Tysabri (natalizumab) became available for people with highly active MS which involved more work for me. In 2008 clinics were started in Thurso and Invergordon. A Neurology Steering Group was started. In 2009 we got a second MS Specialist Nurse and second General Consultant Neurologist. DMTs were increasing along with clinics. In 2010 the MS Register started. We had a MS specialist physiotherapist appointed in 2012 but this was only funded for 2yrs.

Over the years I have seen patients desperate for a cure. People tried Goats serum (Aimspiro), stem cell treatment in Holland, chronic cerebrospinal venous insufficiency (CCSVI) and now stem cells treatment in Moscow. There is a continual lack of provision in MS specialist physiotherapy along with a lack of appropriate respite for the young chronic disabled, no day care for those < 65yrs of age and nothing available to support young mums locally with MS.

In 2013 we had an average of 58 new patients a year, received 1674 telephone calls and made 4697 calls out. We carried out 647 home visits and seen 281 patients in hospital. Clinics have increased to 56 a year throughout NHS Highland. Now we know there are approximately 800 to 900 people with MS in NHS Highland. There are more new drugs available which increases our workload.

NHS Highland has always prescribed all licensed drugs for MS patients ever since they became available and NHS Highland also prescribes Fampyra (fampridine) and Sativex (nabiximols). We also provide patients with Functional Electrical Stimulation (FES) and Lycra suits for ataxia. These are not available in many areas. GPs are more knowledgeable and refer patients much quicker for assessment. Now the MS Specialist nurses are seeing all newly diagnosed and less of severely disabled people. MS Specialist nurses are not able to attend/ access study days so much and only attend one specialist nurse meeting a year. Clinic sessions have grown. Drug companies were more generous with study opportunities in the early years than now. Since the introduction of the MS Register and the Neurological standards our MS service has grown. NHS Highland MS team consist of 2 full time and one part time General Neurologists, 2 MS Specialist nurses and 1 Rehabilitation Consultant."

**Anne Stewart**  
MS Specialist Nurse  
NHS Highland

"I started a new community-based MS Nurse Service in Argyll and Bute just over one year ago. People in this part of the Highlands are usually diagnosed with multiple sclerosis and travel down for neurology review to the Institute for Neurological Science in Glasgow. My aim is to develop a service

which is locally accessible for people and builds on and enhances the service already provided by the MS team in Glasgow.

MS nurses can influence the development of services which support patients and I would like there to be more local MS specialist multidisciplinary rehabilitation services.

I see education provision as an important part of the MS nurse role, as having an understanding of the condition ensures that people and their families are better placed to self manage effectively and Health and Social care providers have the knowledge to support them to do this.

Living with Multiple Sclerosis can mean that, at times, life can be unpredictable and challenging. Multiple sclerosis affects people in different ways. People place value in having a named person who is their first point of contact. At diagnosis, support from the MS nurse soon after the news has been delivered, can make a positive contribution to the ability of the person to process and come to terms with what has been happening to them. The MS nurse can build a relationship with the person over time and can assist them to identify goals to work towards.

The MS Nurse can support self management by signposting or coordinating multi disciplinary needs. Practically this could mean providing information which meets the need at the right time. Or it could mean liaising with the GP about relapse management and symptom control to ensure that people get the appropriate treatment. Updating the neurologist about frequency of relapses ensures that disease modifying therapy (DMT) is prescribed when necessary.

With all the new treatments available now, it can be overwhelming for people (often newly diagnosed) to make decisions, and the MS nurse can assist the patient to make an informed choice about medication. For those on DMT's, the MS nurse can assist with clinical monitoring. For those with progression, who may have lost contact with the neurology team, the MS nurse can ensure an annual review is carried out and that people's ability to function is maximised, healthy behaviours are adopted and that lives are lived to the full and are not defined by the illness.

Starting a MS nurse service in Argyll and Bute has been challenging at times, in the first instance even identifying those with MS in the local area was problematic as data are not readily available. One of my first projects was to ask local GP practices to search on READ codes for MS to identify how many patients were in the local area and then to start to build my own case load. Initially, I focussed on those who had lost contact with multiple sclerosis services and those who were newly diagnosed. Now that I have clinics up and running, I have been able to widen my referral criteria. One year on, I feel that I can now provide a local service to those people who struggle with the tiring journey to Glasgow.

Resources available to patients vary across the area. In Oban, the physiotherapist provides assessments and treatment plans and works in partnership with a third sector group "Healthy Options" who deliver the rehabilitation programme. This works really well and it would be good to provide a similar service in other parts of Argyll and Bute.

In most of the main towns there are very active MS Support Groups. There is enthusiasm to get a support group up and running in Rothesay hopefully soon.

I plan to continue to work collaboratively with NHS, local authority and other agency colleagues to develop and provide an efficient and effective service for MS patients locally."

**Cheryl Howe**

Advanced Nurse MS and Parkinson's Disease, NHS Highland

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# Appendix A Additional Information

Additional information is available on the SMSR website:

Aims, objectives and methods of the audit.

Audit documentation, e.g. data collection forms.

Core dataset definitions.

Current Steering Group members.

Contact details of Project Team.

Previous Annual Reports.

Information on requesting SMSR data for research purposes.

Information on Quality Improvement and Neurological Standards.

Information for patients and carers.

## Appendix B Useful Websites for further information

### **The Scottish MS Register**

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

### **ISD Scotland**

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

### **Healthcare Improvement Scotland**

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

### **MS Society**

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

### **MS Society—What is 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/>

### **MS Society—What is the UK Register?**

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

### **MS Society—UK MS Register Portal**

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

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# Scottish MS Register Contact List

For general questions about the Register please contact the central team.

## Scottish MS Register

Email: [NSS.ISDscottishmsregister@nhs.net](mailto:NSS.ISDscottishmsregister@nhs.net)  
Tel: 0313 314 1209

## Hazel Dodds

Senior Nurse (Clinical Co-ordinator), Scottish Multiple Sclerosis Register  
Scottish Healthcare Audits, National Services Scotland  
Email: [hazeldodds@nhs.net](mailto:hazeldodds@nhs.net)  
Tel: 0131 275 7184

## Amanda Gilmour

Information Analyst, Scottish Multiple Sclerosis Register  
Scottish Healthcare Audits, National Services Scotland  
Email: [amanda.gilmour@nhs.net](mailto:amanda.gilmour@nhs.net)  
Tel: 0141 282 2135

## Martin O'Neill

Principle Information Analyst,  
Scottish Healthcare Audits, National Services Scotland  
Email: [martin.o'neill@nhs.net](mailto:martin.o'neill@nhs.net)  
Tel: 0131 275 6244

If you have general questions about MS care in Scotland please contact Dr Belinda Weller, Chair of the Scottish MS Register.

## Dr Belinda Weller

Chair of Steering Group, Scottish Multiple Sclerosis Register  
Email: [belinda.weller@luht.scot.nhs.uk](mailto:belinda.weller@luht.scot.nhs.uk)  
Tel: 0131 537 2403







