NHS National Services Scotland

Scottish multiple sclerosis register.

National report 2016

Data relating to 1 January 2010–31 December 2015

Contents

Foreword

Multiple Sclerosis (MS) continues to affect the lives of thousands of people across Scotland, and the Scottish Government is committed to improving services, treatment—and outcomes—for people living with MS.

Over its six year history, the Scottish MS Register—a database of confirmed diagnoses of Scottish MS patients—has proved to be an invaluable tool, not only in enhancing our epidemiological understanding of MS, but also in raising standards of treatment throughout the country.

Collating information in this way can greatly aid NHS Boards in planning and implementing high quality service provision, enabling the effective targeting of resources in a number of areas such as specialist recruitment and research. The steady improvement in the standards of MS diagnosis, referral and treatment which we have witnessed over the past few years is a reflection of this.

It is particularly encouraging to see a continued increase in the number of newly diagnosed patients having contact with MS Clinical Nurse Specialists within 10 working days of receipt of referral. This measure is up a further 4% from the previous year and now sits at 89% overall. MS Clinical Nurses are key to providing specialist support and care, especially for newly diagnosed patients.

However, it's also evident that we must intensify our efforts to drive further improvement and there is definitely more work to be done on continuing to raise standards of care.

This Register would not be possible without the positive collaboration and support of analysts and specialist clinical teams throughout Scotland, and I would like to offer my thanks and appreciation for their continued hard work and commitment to the goal of improving the care and treatment for people who live with MS in Scotland.

Dr Catherine Calderwood
Chief Medical Officer

1 Introduction

It gives me great pleasure to introduce the sixth annual report of the Scottish MS Register (SMSR). This Register was established in 2010 and has been collecting data related to new diagnoses of MS since then. Currently data have been recorded for 2,731 people with a verified diagnosis of MS. The Register relies on ongoing support from MS Nurse Specialists, clinicians and managers who submit data on all people with a confirmed diagnosis of MS via a standard paper-based proforma.

As well as capturing important epidemiological data the Register aims to improve healthcare for people living with MS. Establishing the incidence of this condition accurately both nationally and regionally allows for evaluation of available services and for audit against existing standards for MS care (Quality Improvement Scotland (QIS) 2009)[1]. In previous years, data have been collected relating to the availability of contact with MS Nurse Specialists following a confirmed diagnosis and these data have been used in several NHS Boards to justify recruitment of new MS Nurse Specialists when rates of contact were seen to be lower than national averages.

The epidemiological data collected are also being used to investigate why Scotland has one of the highest rates of MS in the world, by allowing comparison of the demographics of our cases to those elsewhere in the world. There are now two clinicians in Glasgow and Dundee working on research projects based around the Register data and the Steering Group as a whole is looking to address issues around consent to facilitate use of the Register for additional research projects including patient reported outcomes.

The responsibility for oversight of the Register rests with the Register Steering Group which includes neurologists, rehabilitation consultants, primary care clinicians, MS Nurse Specialists, AHPs, patient representatives and representatives of voluntary sector organisations. This group works along with staff from the Information Services Division (ISD) of National Services Scotland (NSS) who coordinate the Register nationally and work to validate and report on the data. The Steering Group meets regularly throughout the year to review the progress and direction of the Register.

Presentations of SMSR data have been made at national and international meetings over the last year and we aim to increase awareness of the Register through further presentations and a national meeting to be held later this year in Stirling on 6 October 2016 (for further details refer to the SMSR website—www.msr.scot.nhs.uk).

On behalf of the Steering Group I would like to acknowledge the contribution made since its conception by Dr Paul Mattison who retired earlier this year. Paul acted as co-chair of the Register and contributed with great enthusiasm and his input will be missed.

I would like to thank Stuart Baird and his team at NSS for their continued support and particularly Hazel Dodds who has acted as Clinical Coordinator for the Register for the last 18 months. Hazel has moved on from this role and in her place it is a pleasure to welcome Chrissie Watters to the Clinical Coordinator role. Chrissie has made a great start getting to know as many of the MS clinicians in Scotland as possible with great enthusiasm. Thanks also go to George Mowat-Brown, a member of the Steering Group and chair of the Patient Reference Group (PRG) which provides a patient perspective to the direction of the Register and to Sue Polson, member of the PRG who has joined the Steering Group with great experience of MS research from a patient perspective.

At a time of great demand on the health budget it is increasingly important for the SMSR to show that it is making a difference leading to improvements in the standard of care for people with MS. The data that are collected must be used to improve access to services to ensure that MS services are available uniformly across Scotland. Within the current budgetary constraints the SMSR aims to audit other standards of MS care including availability of annual review and access to appropriate treatments (disease modifying or symptomatic). As a group we will also lobby for up to date Scottish

Guidelines for MS management and to achieve this will aim to work closely with the recently formed National Advisory Committee for Neurological Conditions (NACNC).

To conclude I would like to sincerely thank all of the clinicians and nurses who give their time and effort to contribute data to the SMSR, the members of the Steering Group, all of the staff at ISD for their data analysis and reporting as well as the people with MS who are happy to provide their data.

Dr. Belinda Weller
Neurologist
Chair SMSR Steering Group

1.2 This report

This year's report includes data for 2015 nationally and for each individual hospital/unit managing MS patients in Scotland. The data presented in this report are for patients newly diagnosed with MS.

In summary, there were 530 patients newly diagnosed with MS in Scotland in 2015. Every effort has been made by the central team and the MS Nurse Specialists to improve case ascertainment and provide a true reflection of incidence of MS in Scotland in 2015 though it is acknowledged that some cases may not have been added to the SMSR for various reasons.

Throughout 2015 the SMSR team continued to update and review the analysis of the data collected and modified definitions when necessary, therefore **calculations in this year's report may not match exactly those presented in previous reports**. Scottish, NHS Board and individual hospital data are displayed in charts and tables throughout the report.

1.3 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 NHS Boards and patients across Scotland. In Chapter 6 we present summaries from NHS Boards who have made innovative changes to practice leading to improvement in delivery of care for MS patients and in Appendix B we present information provided by NHS Board Chief Executives highlighting what they are doing locally to improve care for people with MS in their area.

1.4 How MS data are collected

Case ascertainment

The SMSR central team and the MS Nurse Specialists have increasingly cross checked the centrally held SMSR data with routinely collected local data. Any increase in the number of patients diagnosed with MS in 2015 may reflect improvement in case ascertainment, rather than increasing numbers of patients diagnosed with MS. Continuing to improve the checking process will lead to more robust case ascertainment and clearer incidence reporting of MS in Scotland.

Whilst strenuous efforts have been made to maximise data capture for all variables in all NHS Boards, 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. The notes below each table/ chart will highlight any particular areas of data incompleteness known to the team.

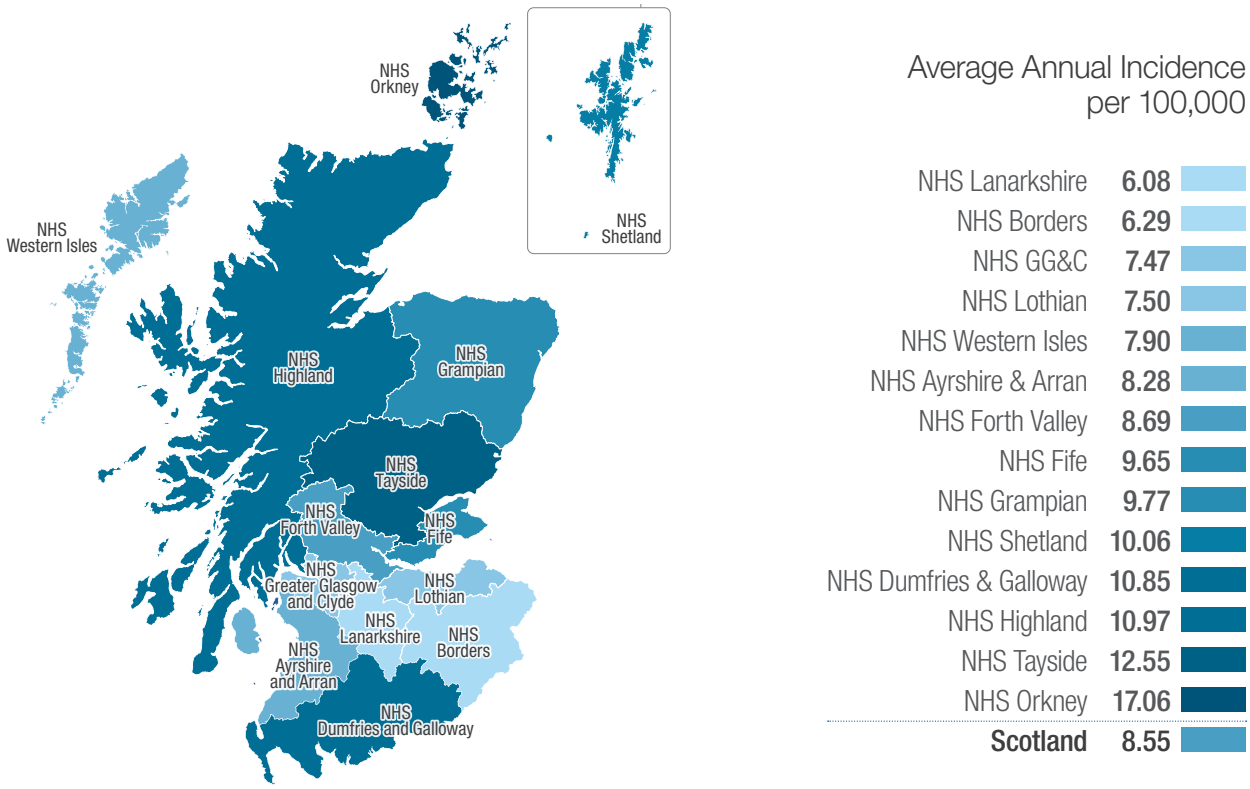
2 Overview of 2015

All NHS Boards within Scotland have contributed data to the MS Register over the past 6 years. The average reported annual incidence per 100,000 of the population by NHS Board over 2010–2015 is illustrated in the map below (Figure 1). This shows the highest average reported annual incidence (per 100,000 population) in NHS Orkney in a dark blue through to lowest average annual incidence in NHS Lanarkshire in light blue.

There is a noted latitudinal gradient in MS prevalence worldwide, with, in general, more people with the disease further from the equator[2], which is supported by data from the Scottish MS Register. The average annual incidence in the six most northern NHS Boards (Shetland, Orkney, Highland Western Isles, Grampian and Tayside) is 11.39 (range 7.90–17.06) per 100,000 population, which is statistically significantly higher (p=0.03) than the remaining eight southern NHS Boards (average annual incidence 8.10, range 6.08–10.85). This result remains even when Orkney, as a potential statistical outlier, is removed from the calculation, which suggests Orkney is contributing to, rather than explaining, the north south effect.

This interesting initial finding is supported by more detailed methodology described in Research Section 5.2. It will be further explored and validated over the coming year. It should be noted that the early years of data collection varied between NHS Boards and so could explain some of the result.

Figure 1 Average annual incidence of patients newly diagnosed with MS per 100,000 population, **2010–2015 data** (by NHS Board).



Notes:

1. Average (mean) population estimates across the 6-year time period used for this figure 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 annual incidence of MS per 100,000 population across the 6-year time period is calculated using mean mid-year population figures and the mean annual number of newly-diagnosed patients residing in each NHS Board.
3. Darker colours indicate a greater average annual incidence per 100,000.

2.1 Results and Main Findings

This years report includes data for Scotland overall and for each local hospital/unit managing MS patients. In 2015 there were 530 patients with a confirmed diagnosis of MS reported which is a considerable increase on the numbers reported in previous years. Whether this represents an actual increase in the number of cases diagnosed or improved case ascertainment is not known. The SMSR team and their auditors continue to cross check the SMSR data with routine locally collected data with an aim to optimise incidence reporting in all areas of Scotland.

In the six years of data collection, 2,731 cases of MS have been reported and included on the Register database. This represents a mean national incidence rate over the last six years of 8.55 per 100,000 population with the highest incidence of 17.06 per 100,000 reported in NHS Orkney and the lowest of 6.09 per 100,000 reported in NHS Lanarkshire.

The mean national incidence rate, although increased from previous years is still lower than reported in earlier studies based in Scotland. Rothwell and Charlton (1998)[3] established crude annual incidence rates of 12.2/100,000 in the Lothian region and 10.1 in the Borders region. However, this study included people without a definite diagnosis of MS and also included paediatric cases which the SMSR does not currently include, although this could be considered as a collaboration with our paediatric neurology colleagues in the future. The reported incidence rate is nonetheless considerably higher than that reported in most other countries and particularly in other UK countries.

The female to male ratio of newly diagnosed cases in Scotland has remained very stable over the six years of the Register, and is calculated at 2.3(f):1(m) for 2015. Our data have not reflected the trend for an increase in the female to male ratio which has been reported in other parts of the world[2,4]. The SMSR continues to audit rates of and time to contact with MS Nurse Specialists after diagnosis.

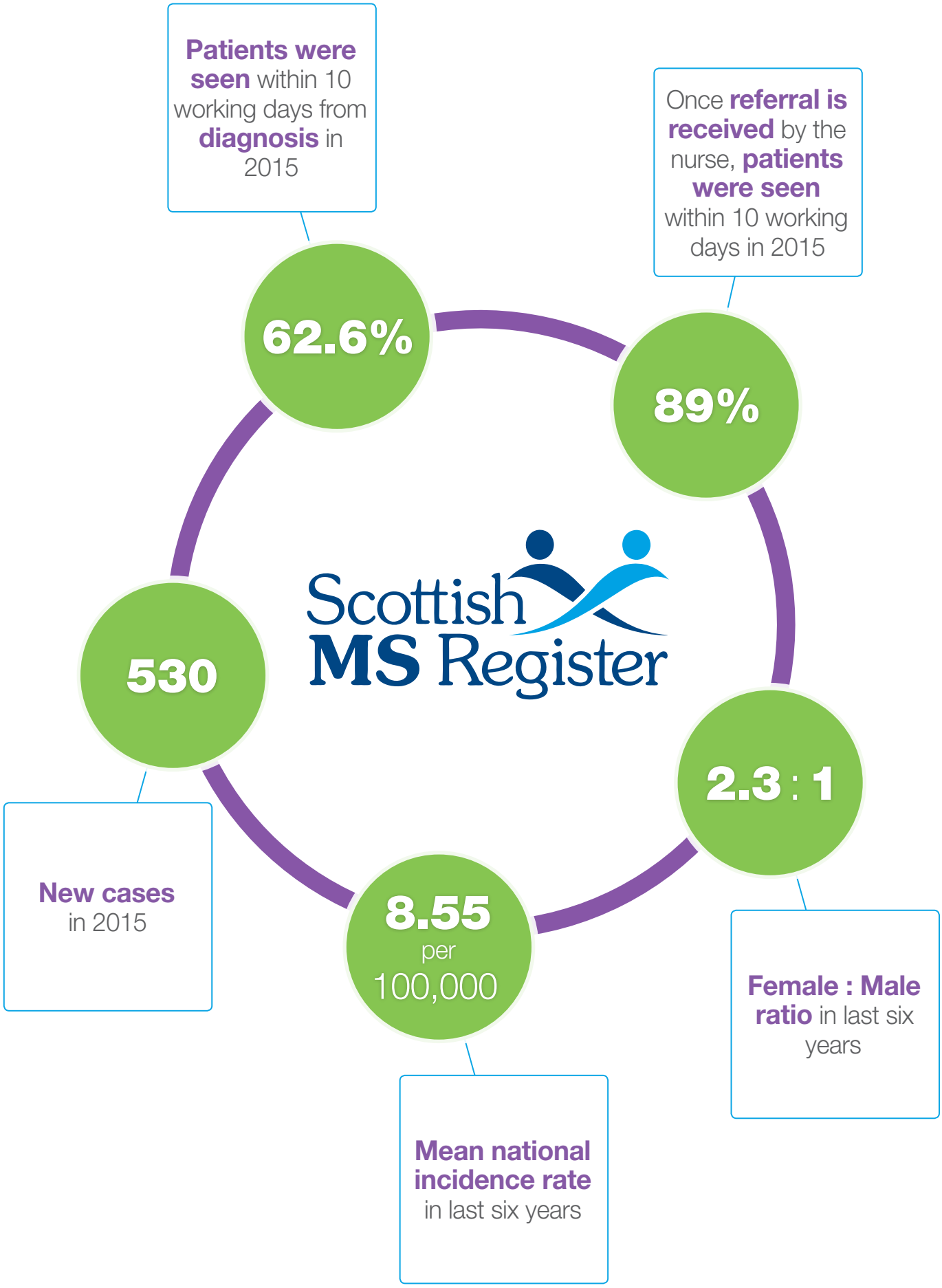
The percentage of cases meeting HIS clinical standard 15.2 (which states “Contact with a MS Nurse Specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of the diagnosis”) has shown a slight increase at 62.6%. This reflects the fact that not all diagnoses of MS are made in specialist MS clinics with ready access to Nurse Specialists. Many diagnoses are made by general neurologists in district general hospitals and remote areas, and referral to Nurse Specialists may be delayed by administrative factors or clinician preference. Cases where contact is declined by the newly diagnosed person are not counted, which could also influence this figure.

It is very heartening however that when MS Nurse Specialists receive a referral of a new MS diagnosis, 89% of people are contacted within 10 working days. This figure has seen a further improvement up from 85% last year. This figure more appropriately reflects the excellent work that MS Nurse Specialists are doing to support people with MS around the time of diagnosis and for this reason we continue to collect these data.

It also highlights the need to publicise the SMSR to all clinicians involved in the diagnosis of MS to inform them of the HIS standard 15.2 to encourage timely referral to MS Nurse Specialists.

Figure 2 provides a summary of the main points from the SMSR data for 2015.

Figure 2 Summary of main points



3 Neurological Standards (2009)

Standard 15.2 of the Clinical Standards for Neurological Health Services (2009) states that following a diagnosis of MS: “Contact with a MS Clinical Nurse Specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of the diagnosis”.

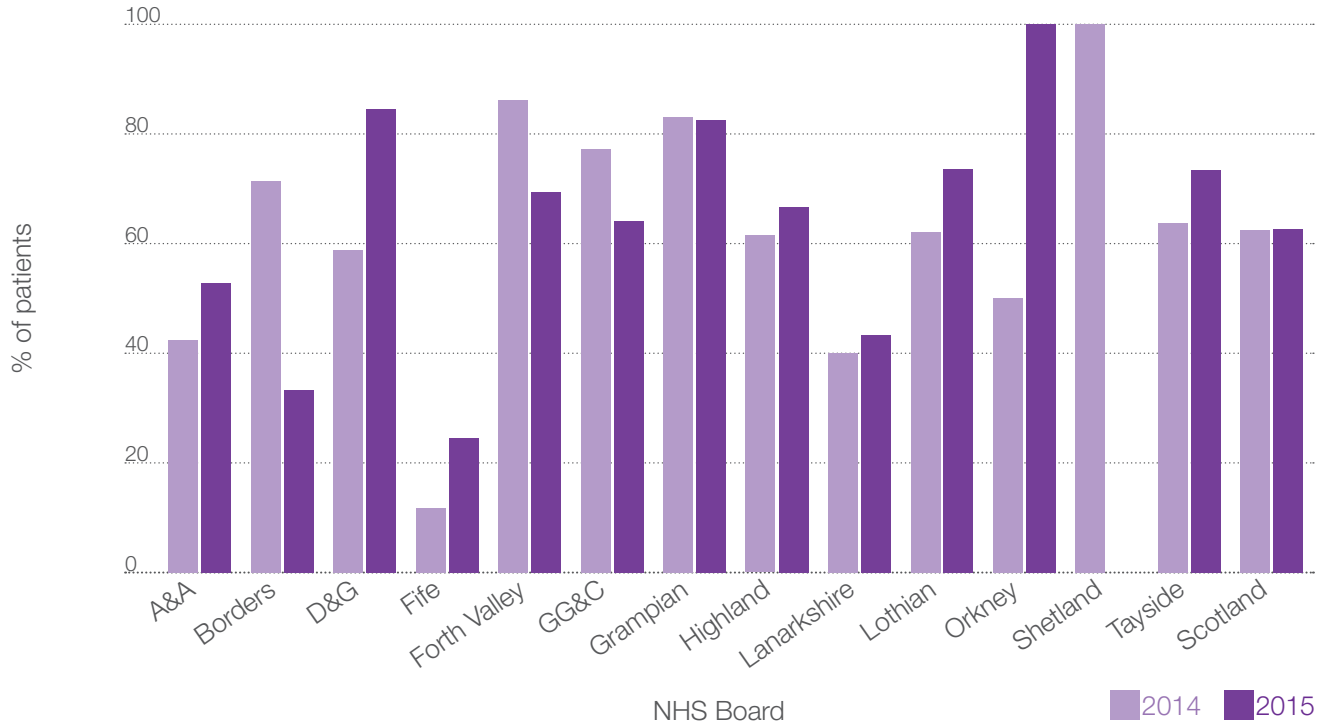
62.6% of patients had contact from the MS Nurse Specialist within 10 working days following confirmed diagnosis.

It is pleasing that the percentage of patients contacted within 10 working days of confirmed diagnosis has increased by over 10% since 2010 but there remains considerable scope for improvement. The emotional difficulty and need for clear, balanced information around the time of diagnosis is well documented and MS Nurse Specialists are expertly trained to provide support and advice at this stage. Measures to improve early contact with a MS Nurse Specialist at diagnosis could include development of standardised diagnostic pathways and increased use of electronic referral systems. Communication between clinicians diagnosing MS and MS Nurse Specialists should be facilitated.

Access to Nurse Specialists varies depending on where the diagnosis is made and is influenced by geographical factors and also by staffing levels. Over the last year there have been new MS Nurse Specialists recruitments to Fife, Glasgow and Grampian which will hopefully facilitate earlier contact with MS patients.

It is hoped that use of the SMSR will allow service managers to see where national standards are not being met within their Boards as a result of inadequate staffing and so use the figures as leverage to correct these problems.

Chart 1 Percentage of patients with a new diagnosis of MS contacted by a MS Nurse Specialist within 10 working days of confirmed diagnosis, **2014–2015 data**



Notes:

1. Cases for which contact with a MS Nurse Specialist was declined (N < 5) have been excluded from the data presented in this chart.
2. Data for this chart are based on NHS Board of residence. Consequently, this may not be an accurate representation of each NHS Board's performance as some patients may have chosen to be treated under a NHS Board area other than that in which they reside.
3. No new diagnoses of MS have been reported in NHS Western Isles in 2014 or 2015
4. No new diagnoses of MS have been reported in NHS Shetland in 2015

62.6% of patients had contact from the MS Nurse Specialist within 10 working days following confirmed diagnosis compared to **89%** once the nurse had received the referral.

Neurological Standard: Contact with a MS Clinical Nurse Specialist is offered at diagnosis to patients with MS and contact is made within 10 working days of diagnosis.

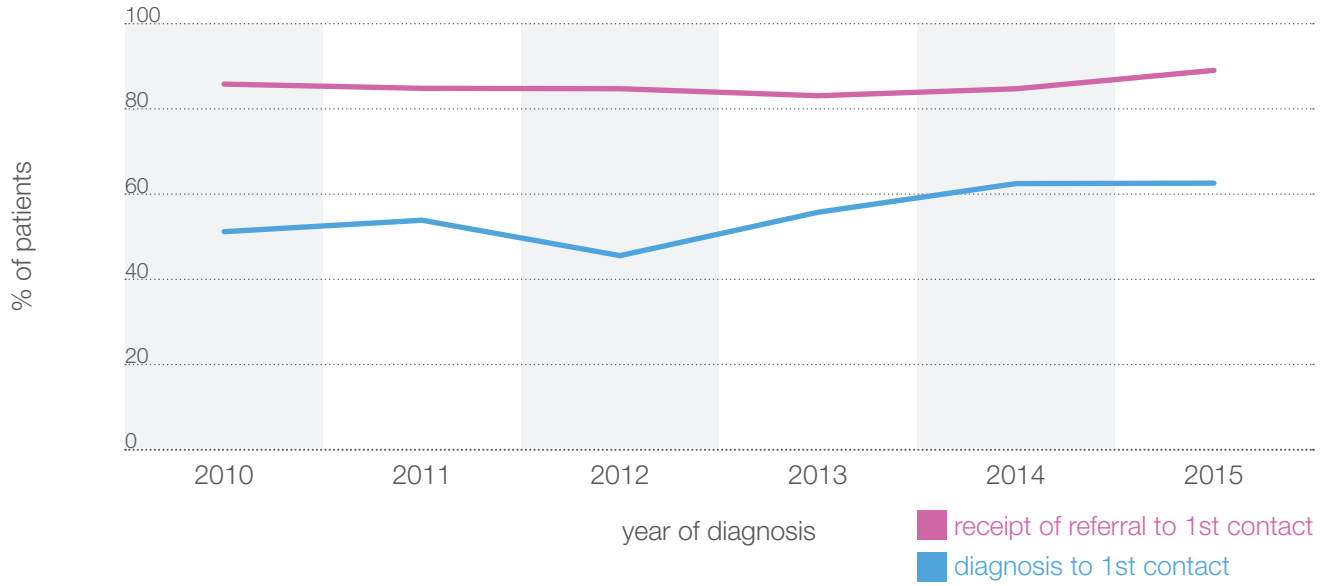
Chart 2 demonstrates that once the MS Nurse Specialists have received a referral, they are able to make contact within 10 working days 89% of the time, which is very commendable. The fact that contact is made within 10 working days of diagnosis in only 62.6% of cases reflects the different pathways to diagnosis that exist throughout Scotland.

In many NHS Boards a diagnosis of MS is made by general neurologists who then make the onward referral to specialist MS teams. These specialist teams may be based at different locations. Much of the delay in these cases reflects time taken by the diagnosing physician to make the referral and for it to be received by the MS Nurse Specialists.

Reduction in delay from diagnosis to first contact with a MS Nurse Specialist could be made by having designated MS diagnostic clinics with MS Nurse Specialists present and also by introduction of electronic referral systems.

It needs to be recognised as well that a certain number of people with a new diagnosis of MS reject contact with a MS Nurse Specialists and at present this is not recorded.

Chart 2 Percentage of patients with a new diagnosis of MS contacted by a MS Nurse Specialist within 10 working days of confirmed diagnosis Vs percentage contacted within 10 working days from receipt of referral, **2010–2015 data**

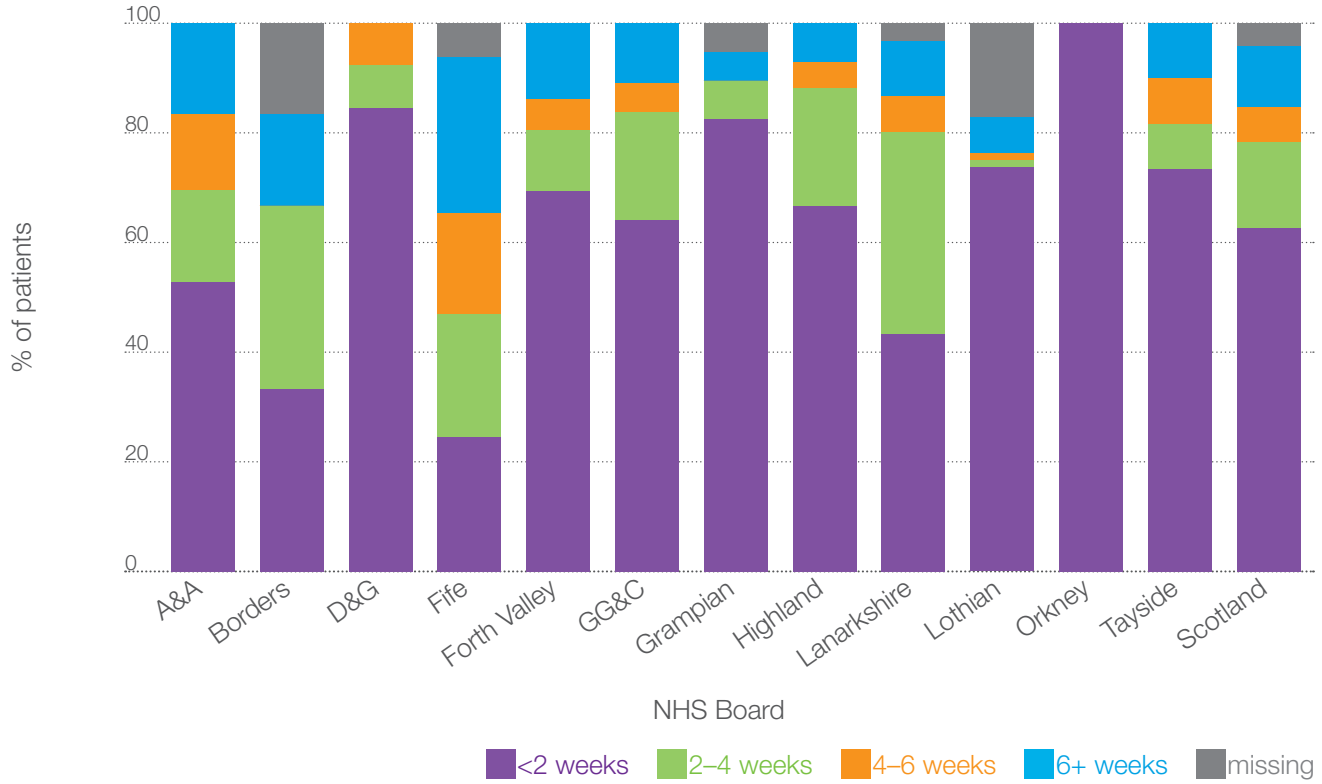


Notes:

1. Cases for which contact with a MS Nurse Specialist was declined (N=27) have been excluded from the data presented in this chart.
2. Cases for which patients received a confirmed diagnosis from a consultant neurologist outwith Scotland (N<5) have been excluded from the data pertaining to the number of weeks between confirmed diagnosis and 1st contact.
3. Cases with incomplete/missing date of confirmed diagnosis (N=9) have been excluded from the data presented in this chart.

Chart 3 also presents time from diagnosis to contact with a MS Nurse Specialist throughout Scotland. This uses the NHS Board of residence of each patient but does not take into account that many patients will be diagnosed in a NHS Board in which they are not resident. This may lead to longer times to referral and first contact with a Nurse Specialist. Overall 62.6% of patients with a new diagnosis of MS were seen within 10 working days from diagnosis which is an improvement from last year.

Chart 3 Percentage of patients newly diagnosed with MS in Scotland, by number of weeks from confirmed diagnosis to first contact with a MS Nurse Specialist, **2015 data**



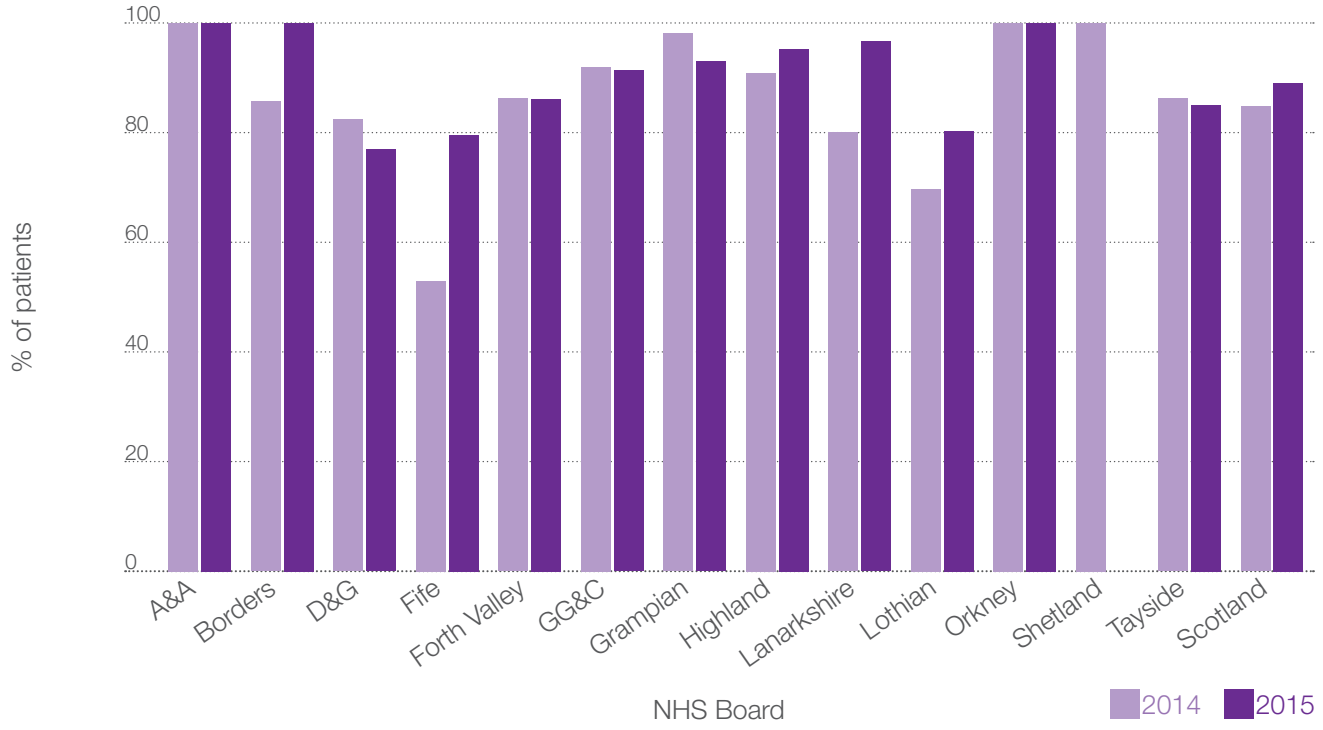
Notes:

1. Cases for which contact with a MS Nurse Specialist was declined (N<5) have been excluded from the data presented in this chart.
2. Data for this chart are based on NHS Board of residence. Consequently, the above may not be an accurate representation of each NHS Board's performance as it is possible that a proportion of patients will choose to be treated under a NHS Board area other than that in which they reside.
3. NHS Western Isles and NHS Shetland do not appear in the above as they have declared no new diagnosis of MS for 2015.

89% of patients had contact from the MS Nurse Specialist within 10 working days of receipt of referral.

Chart 4 illustrates that when MS Nurse Specialists receive a referral of a new MS diagnosis that they are very effective in making contact. 89% of people were contacted within ten days of the referral being received which is an excellent result particularly given that this does not include those patients who declined contact.

Chart 4 Percentage of patients with a new diagnosis of MS contacted by a MS Nurse Specialist within 10 working days of receipt of referral, **2014 and 2015 data**

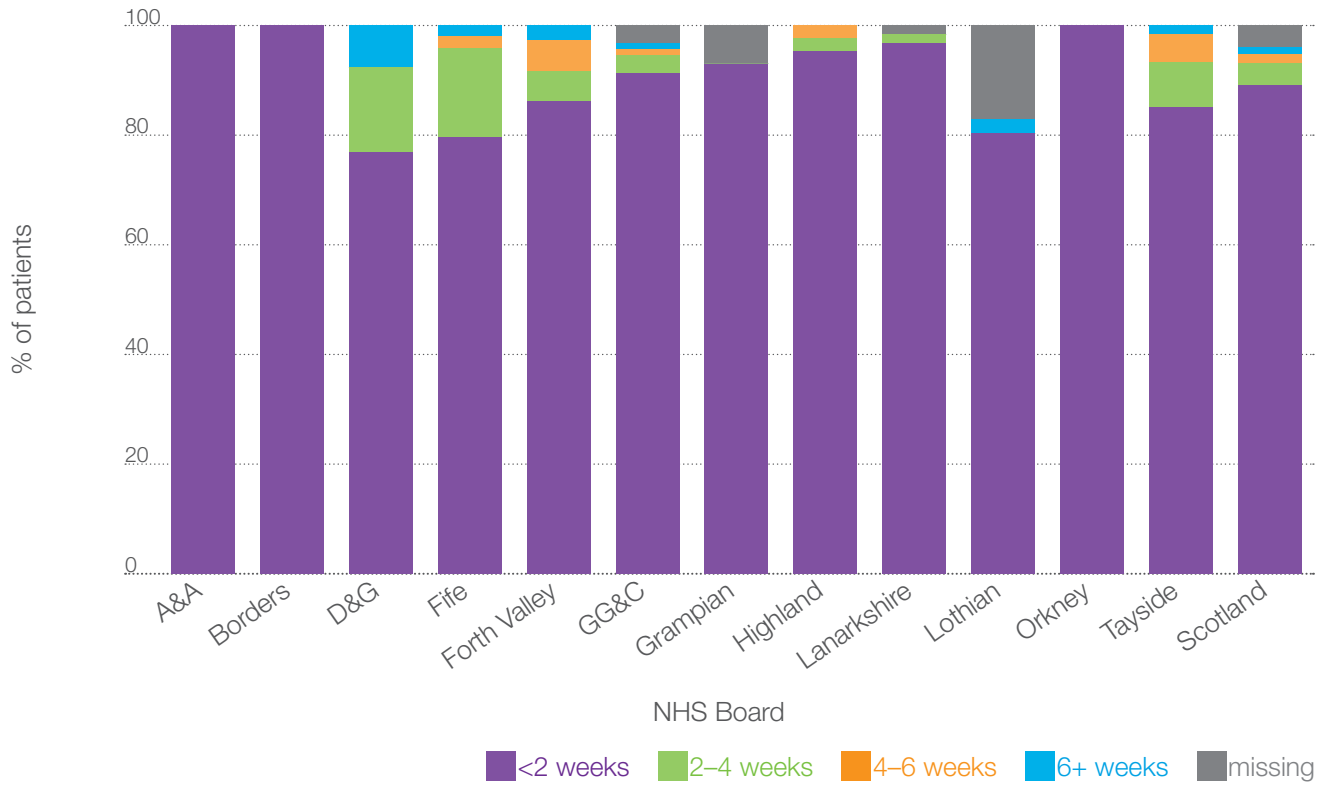


Notes:

1. Cases for which contact with a MS Nurse Specialist was declined (N<5) have been excluded from the data presented in this chart.
2. Data for this chart are based on NHS Board of residence. Consequently, this may not be an accurate representation of each NHS Board's performance as some patients may have chosen to be treated under a NHS Board area other than that in which they reside.
3. No new diagnoses of MS have been reported in NHS Western Isles in 2014 or 2015.
4. No new diagnoses of MS have been reported in NHS Shetland in 2015.

Chart 5 also shows time taken from receipt of referral by a MS Nurse Specialist to first contact, which is within 10 working days 89% of the time. This is an improvement of 4% from last year. Several NHS Boards have submitted incomplete data and attempts will be made to document time for all contacts.

Chart 5 Percentage of patients newly diagnosed with MS in Scotland, by number of weeks from receipt of referral to first contact with a MS Nurse Specialist, **2015 data**



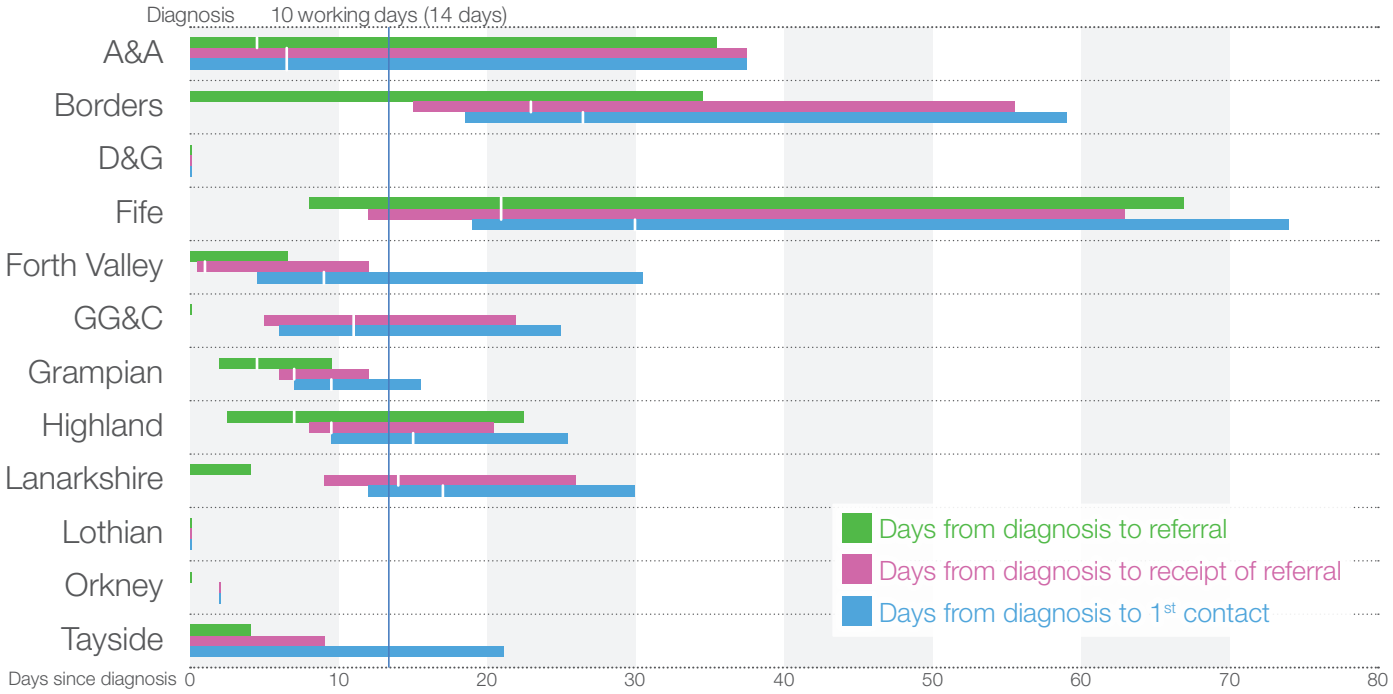
Notes:

1. Cases for which contact with a MS Nurse Specialist was declined (N<5) have been excluded from the data presented in this chart.
2. Data for this chart are based on NHS Board of residence. Consequently, the above may not be an accurate representation of each NHS Board's performance as it is possible that a proportion of patients will choose to be treated under a NHS Board area other than that in which they reside.
3. NHS Western Isles and NHS Shetland do not appear in the above as they have declared no new diagnosis of MS for 2015.

Chart 6 shows the time taken for each stage of the referral process after a diagnosis of MS is made and the variation in these data reflect the different diagnostic pathways in different centres. In centres where diagnosis is made in a designated MS clinic a referral is often made to the MS Nurse Specialist at the time of diagnosis and the patient may have the chance to meet the nurse as soon as the diagnosis is made.

Across Scotland there is a large delay between the diagnosis and receipt of referral by the MS Nurse Specialists and ways to expidite this have previously been discussed. Once again this chart does not allow for the fact that some patients are diagnosed in a NHS Board where they are not resident and may be referred back to that NHS Board for ongoing follow-up.

Chart 6 Average number of days between each stage in the referral process from diagnosis to first contact by a MS Nurse Specialist, **2015 data** (by NHS Board)

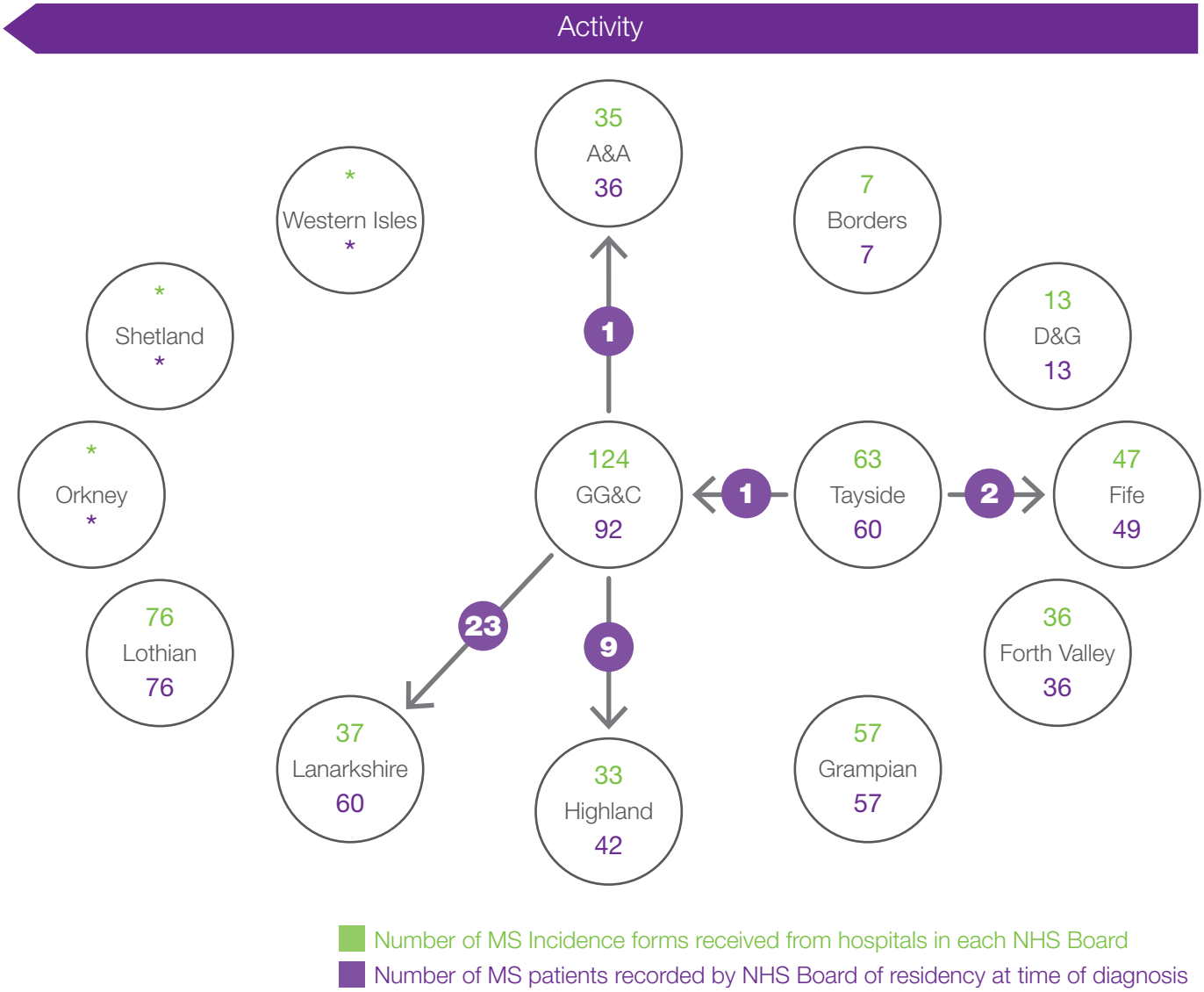


Notes:

1. For chart 6, a box plot has been used to show the typical time distribution (in days since diagnosis) for each stage in the referral process for patients diagnosed in 2015. Each box shows the **interquartile range**, or middle 50% of the data. The white line inside each box shows the **median** number of days between diagnosis and each stage in the referral process. As the data are largely skewed, the median is more representative of the typical patient experience than the mean as it is less influenced by outliers. The minimum and maximum values are not necessarily shown in this chart.
2. Chart 6 illustrates, for example, that the average (median) patient residing in the NHS Tayside area had their referral sent to a MS Nurse Specialist, that the MS Nurse Specialist received the referral, and that the patient had their first contact with the MS Nurse Specialist all on the same day as they received a confirmed diagnosis. If we take the interquartile range to indicate the typical patient experience, typically, a patient residing in NHS Tayside had their referral sent to a MS Nurse Specialist between 0 and 5 days following diagnosis, the MS Nurse Specialist received the referral between 0 and 9 days following diagnosis, and the patient had their first contact with the MS Nurse Specialist between 0 and 21 days following diagnosis.
3. Cases for which contact occurred or the referral was sent or received prior to diagnosis (N=47) and cases with incomplete date of confirmed diagnosis recorded (N=9) have been excluded. Cases for which contact was declined (N<5) have been excluded.
4. Data for this chart are based on NHS Board of residence. Consequently, the above may not be a true representation of each NHS Board's performance as it is possible that a proportion of patients will choose to be treated under a different NHS Board area than that in which they reside.
5. NHS Western Isles and NHS Shetland do not appear in the above as they have declared no new diagnosis of MS for 2015.

Figure 3 demonstrates the fact that there is a lot of cross NHS Board activity with regards to MS diagnosis and completion of MS Register forms. NHS Greater Glasgow and Clyde for example is involved in the MS diagnosis of patients from NHS Lanarkshire, Highland and Ayrshire and Arran.

Figure 3 Number of patients with a new diagnosis of MS by NHS Board from which we receive incidence forms vs NHS Board of residence at time of diagnosis, **2015 data**



Notes:

1. The purpose of figure 3 is to illustrate cross border activity between NHS Boards.
2. This figure illustrates, for example, that 124 MS patient incidence forms were collected from participating hospitals under NHS GG&C in 2015. 92 patients resided under the NHS GG&C area at the time of their confirmed diagnosis, 9 resided under the NHS Highland area at the time of their confirmed diagnosis, 23 resided under the NHS Lanarkshire area at the time of their confirmed diagnosis, and 1 patient resided under the NHS Ayrshire & Arran area at the time of their confirmed diagnosis. 1 patient incidence form for a patient residing under the NHS GG&C area was received from NHS Tayside.
3. Note that we now receive incidence forms directly from NHS Orkney, although diagnoses for these patients are typically made in NHS Grampian.

* Following ISD Statistical Disclosure Protocol, any cells with count values of 4 or less have been suppressed in order to protect the confidentiality of potentially personally identifiable information

3.1 Demographics

A total of **2,731** people have been diagnosed with MS and reported to the Scottish MS Register from 1 Jan 2010 to 31 Dec 2015.

The number diagnosed has increased from **447** in 2014 to **530** in 2015.

530 newly diagnosed cases of MS were reported to the Scottish MS Register in 2015, which is the highest number since the Register was started in 2010. It is uncertain as to whether this represents an increasing incidence or whether this is due to improved case ascertainment. If the numbers of newly diagnosed MS cases are increasing, this will have implications for service development, in particular with a need for additional MS specialists, doctors, nurses and allied health professionals, and increased numbers of clinic appointments if HIS standards of care are to be met.

Table1 below shows that the number of people being reported to the MS Register has increased since 2014, however as noted in section 2.1 this could be due to improved case ascertainment rather than an increase in the number of people diagnosed with MS in 2015.

Table 1 Number of patients newly diagnosed with MS in Scotland, **2010–2015 data**, reported by NHS Board of residence

NHS Board	Year of Diagnosis					
	2010	2011	2012	2013	2014	2015
NHS Ayrshire & Arran	16	29	34	37	33	36
NHS Borders	8	7	7	7	7	7
NHS Dumfries & Galloway	12	16	15	25	17	13
NHS Fife	28	28	34	39	34	49
NHS Forth Valley	17	23	25	26	29	36
NHS Grampian	54	49	60	65	53	57
NHS Greater Glasgow & Clyde	95	83	82	83	75	92
NHS Highland	36	23	29	37	44	42
NHS Lanarkshire	48	30	46	29	25	60
NHS Lothian	60	54	50	74	67	76
NHS Orkney	5	5	5	*	*	*
NHS Shetland	*	6	*	*	*	*
NHS Tayside	42	42	56	51	59	60
NHS Western Isles	5	*	*	*	*	*
Total	430	397	447	480	447	530

Notes:

1 9 patients were excluded from this table due to an incomplete/missing date of confirmed diagnosis.

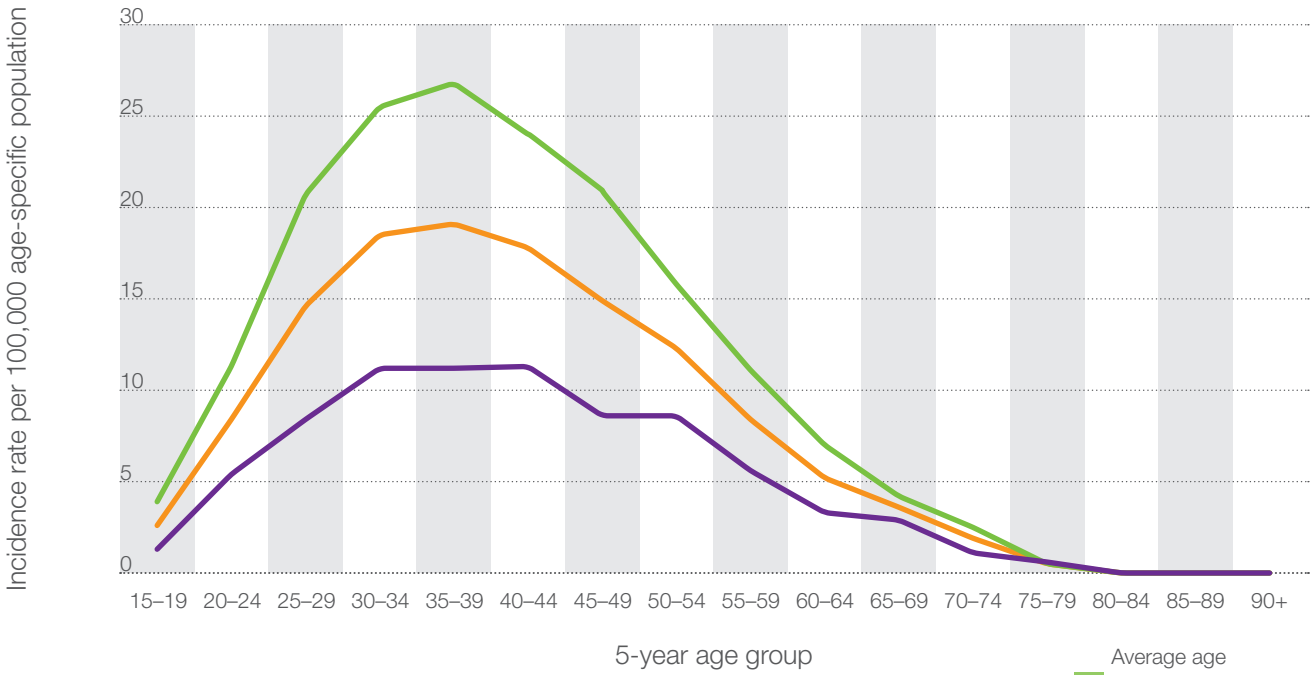
* Following ISD Statistical Disclosure Control Protocol, any cells with count values of 4 or less have been suppressed in order to protect the confidentiality of potentially personally identifiable information.

The mean age of diagnosis is **41** years old.

Chart 7 illustrates the mean age of diagnosis for all newly diagnosed cases in 2015 as well as the mean ages for newly diagnosed female and male patients. This is unchanged from last year with an average age of 41 years for female patients and 42 years for male patients. This is higher than previously reported in Scotland. Rothwell and Charlton reported a mean age at diagnosis of 34 years in 1998[3]. It does however compare with the results of a UK wide survey of MS from primary care records in 2015[5] which found a mean age at diagnosis of 42.

The relatively higher age at 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 higher rates of progressive disease along with increased rates of co-morbidities which may lead to increased costs of health and social care especially in the absence of any effective disease modifying therapy for progressive MS.

Chart 7 Average annual age specific incidence of patients newly diagnosed with MS in Scotland per 100,000 population, **2010–15 data** (by gender)



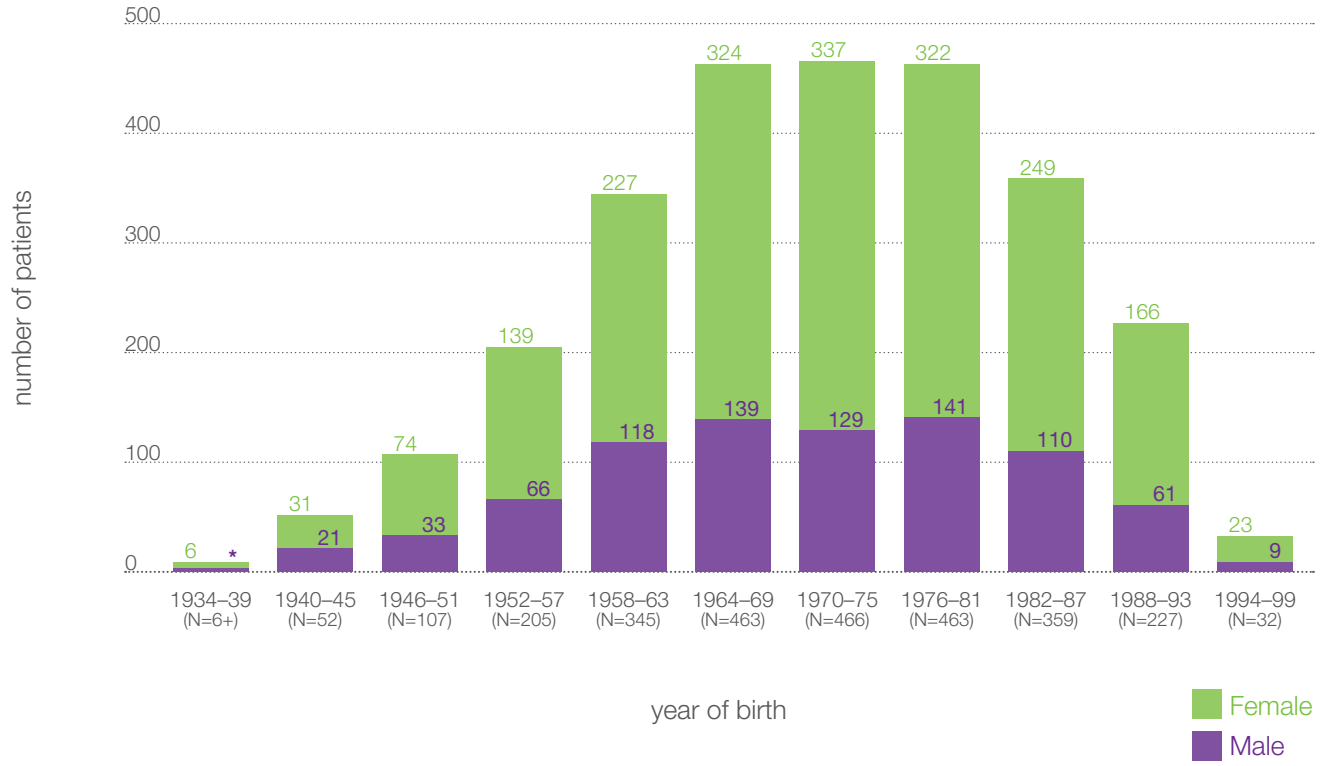
Notes:

1. Arithmetic mean age for gender is calculated using patients date of birth quoted at time of confirmed diagnosis.
2. SMSR collects data on newly diagnosed patients aged 16 years and over.
3. Average annual incidence within each age group was calculated using the mean mid-year gender population estimates within each 5-year age group for 2010–2015 (from the General Register Office for Scotland, estimated for the 30 of June each year) and mean incidence reported to the Scottish MS Register for each gender across this 6-year time period.
4. Cases for which age at diagnosis could not be calculated (N=34: N_{males}=10, $N_{females}$=18, $N_{unknown}$=6) were excluded from the data presented in this chart.

Since 2010 there are **2.3** females to every male diagnosed with MS.

Chart 8 shows that the female to male ratio of people with a new diagnosis of MS remains very stable in Scotland at 2.3(f) to 1(m). This continues to be in contrast with studies from other parts of the world which have suggested a significant shift in the female to male ratio with Simpson et al (2011)[2] and Trojano et al (2012)[4] reporting such a trend in the UK and Northern Europe respectively.

Chart 8 Number of patients newly diagnosed with MS in Scotland, **2010–2015 data** (by gender and year of birth)



Notes:

1 Cases where a patient's date of birth was not recorded (N=12) have been excluded from the data presented in this chart.

* Following ISD Statistical Disclosure Control Protocol, any cells with count values of 4 or less have been suppressed in order to protect the confidentiality of potentially personally identifiable information.

4 Use of primary care data to determine prevalence

Lanarkshire MS Census

The exact incidence and prevalence of MS in Lanarkshire is uncertain. Dr Chris Mackintosh and colleagues attempted to clarify the number of people with MS by contacting all of the GP practices in Lanarkshire and asking them for details of their patients.

Responses were received from 77 of 110 practices (70% of practices in Lanarkshire). These practices reported 1,176 cases of MS with an average of 15.3 cases per practice. There did appear to be some geographical variation in prevalence of MS. We cannot explain this.

The numbers of patients diagnosed with MS per year were higher in the GP data compared to the MS Register data. It is uncertain why this is as we could not look at notes for individual patients. This could be due to under-reporting to the Register or diagnostic issues in the community.

These figures show that Lanarkshire has a large ageing population of people with a diagnosis of MS and that most people are diagnosed between the age of 25 and 45 years. This study shows that prevalence studies like this are feasible but that not all GP practices will respond and become involved. At present there is no contractual mechanism that would make GPs report MS.

5 Research

Utilisation of data within the Scottish MS Register is thought to be a vital aspect of our understanding the impact MS has on 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 was established.

5.1 The SMSR Research Sub-group

The group has representation from throughout the country with neurologists, public health consultants/epidemiologists, members of the public and information analysts.

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) Authorising 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 research projects utilising SMSR data

There are a number of ongoing research projects. An ongoing issue has been the subject of consent. The MS Register was formed as an audit tool and there was no consent obtained from patients for their inclusion. One of the major problems with using the SMSR as it exists currently is the lack of explicit consent to use NHS data for research, despite the advantages that NHS Scotland has in electronic data terms compared to other parts of the world. As of 1 January 2016, a new question was added to the MS Register Proforma asking "has the patient noted that they would be happy to be contacted to discuss potential involvement in research studies in the future?" Feedback on this question has not been very positive. The steering group has agreed that it would be desirable to contact patients via their physicians in order to invite them to participate in any potential research initiatives.

(1) Dr James McDonald is about to submit his MSc and has undertaken three specific projects.

A **Deprivation and MS Case Spread**

The association of MS Incidence with deprivation is poorly understood. This study compared both MS Incidence and MS Case spread and with deprivation in Scotland from 2010–2015.

Results: 2,536 patients were analysed. Median number of cases per datazone was 126.8. Comparing observed and expected numbers using chi-sq: p=0.012. 1,186 (46%) patients were identified as coming from high deprivation vs. 1,350 (54%) patients from low deprivation. Comparing this to an expected equal spread using Fisher's Test p=0.02 (OR 95%CI). Comparing incidence rates revealed non significant differences (Chi Sq p= 0.156, Fisher's p=0.24).

Conclusion: The data suggest that more MS cases have occurred from less deprived areas over the last 5 years and that case spread is not equal. Correcting for population did not yield significant differences suggesting that MS incidence may not be significantly affected by deprivation.

B Variance of MS Incidence Rate with latitude in Scotland.

Methods: All cases from the SMSR with a diagnosis date between 2010–2015 were analysed. Each case was linked to a datazone from SIMD giving co-ordinates of latitude and longitude for each case. Latitudes were converted from degrees, minutes and seconds into a decimal range. The range of latitude was split into groupings of one degree difference and the total number of MS cases and total background population for each latitude grouping was calculated. Incidence rates per 100,000/year were then calculated for each group. An ANOVA analysis of variance was carried out to test for statistical significance of the differences. Statistical significance was taken as $p<0.05$.

Results: 6,505 datazones were identified. Datazone latitude ranged from 54.69006 (54d 41m 24s N) to 60.7187133 (60d 43m 7s N). Datazones were grouped by latitude into six groups by latitude banding. Overall 2,536 MS cases were identified, the range for the six groupings was 14–1,717. Population per datazone ranged from 0–7,524 (Mean=803). MS Incidence (per 100,000 per year) for the groups ranged from 9.9 to 20.5 (mean=13.2). One-way ANOVA showed a significant difference between groups ($p<0.005$)

Conclusion: MS Incidence Rate (cases/100,000/yr) tends to increase with latitude. The highest peak of MS Incidence appears to be overlying south Orkney.

C Deprivation and Engagement with MS Services

Introduction: Deprivation has been associated with a number of adverse health outcomes. For MS in Scotland, there is a target time of <10 working days (14 days) between diagnosis and contact with a MS Nurse Specialist. We explored the impact of deprivation on waiting time to see a MS Nurse Specialist.

Background: The Scottish Index of Multiple Deprivation 2012 (SIMD) is a tool for identifying relative deprivation across geographical areas in Scotland. It creates an aggregate measure of deprivation for 6,505 individual areas. Areas are ranked from most deprived to least deprived and split into 20 vigintiles (1=5% most deprived to 20=5% least deprived). The Scottish MS Register (SMSR) is a Register of new diagnosis of MS occurring after 1 January 2010. Data recorded in SMSR include location data, date of diagnosis, date of contact with MS Nurse Specialists.

Methods: Data on newly diagnosed cases of MS for the last 5 years (2010–2015) were obtained from the SMSR and were collated with SIMD to assign each MS case with a deprivation vigintile. Cases were placed into 2 groups (High deprivation = Vigintiles 1–10, Low Deprivation = Vigintiles 11–20) and average wait (days) to see a MS Nurse Specialist was calculated for each group. This was then split into <14 days or >14 days. Fisher's test was used to calculate the significance of the difference between groups. Statistical Significance was taken as $p<0.05$.

Results: In the high deprivation group (n=1,165), 587 patients (50.4%) were seen before 14 days vs 718 patients (54.4%) for the low deprivation group (n=1,320). The difference was significant (p=0.049, OR 0.85, 95% CI 0.727-1).

Conclusion: Patients from more deprived areas are more likely to wait longer than the government target of being seen by MS Nurse Specialists within 10 working days from diagnosis.

(2) Dr Kerr Grieve is undertaking this project as part of his PhD in the Medicines Monitoring Unit (MEMO) in Dundee supervised by Prof Tom McDonald and Dr Jonathan O'Riordan. He has developed a web based questionnaire exploring the type of potential research projects to be addressed. This is in conjunction with Prof John Zajicek at the University of St Andrews. This project is expected to answer the issue of consent.

(3) Other ongoing projects are evaluating the differences between areas of high DMT prescribing and low presciribing and the course of MS. This project is seeking ethics approval and is ongoing through the centres in Glasgow and Aberdeen.

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 www.msr.scot.nhs.uk/Research/Main.html and email it to NSS.isd-ScotHealthAudits@nhs.net.

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

MS Support Nurse—Douglas Grant Rehabilitation Centre, Irvine

At the Douglas Grant Rehabilitation Centre the number of patients on treatments has continued to increase and for the two MS Nurse Specialists (MSNSs) this has meant an increase on safety monitoring, caretaking and information about Disease Modifying Therapies (DMTs). The rapidly growing day case infusion treatment service was covered by the rehabilitation ward staff to ease the burden on the MSNSs but this in turn had an impact on the inpatient service.

In 2014 a proposal was made via the Pharmaceutical industry to request funding for a MS Support Nurse post. This post would manage and streamline day case treatments, be responsible for the monitoring of new high risk therapies and free up time for the MSNSs to enable more face-to face time with patients—both those on treatments and those not meeting criteria for DMTs.

Anne took up post as MS Support Nurse on 1 June 2015. This has made a huge impact on the team and has steadily developed new skills for Anne on top of her existing high level of experience. This post has brought a single point of contact for the many patients Anne sees and/or speaks with on a daily basis. Seeing the same person each month makes it easier to recognise when a patient is not as well and then put a plan in place for care, which may include infection screening, offering support and advice or onward referral to another member of the MS team. Often having one to one support allows patients time to be more open and honest about the issues affecting them. It has on occasion prevented multiple unnecessary appointments with other health professionals. Patients prefer the continuity and feel well supported and informed.

Since in post, Anne has continued to develop her role to support patients on DMTs. She acts as a resource for the ward staff as well as for people affected by MS within the inpatient ward. This has enabled the team to develop the MS service; offering peripheral clinics closer to the patient's home and increased education for those affected by MS in community settings.

Patients on high risk treatments benefit from a single point of contact and appreciate this in their feedback in the "YOU SAID, WE DID" forms. Some of the patient comments include:

> "Anne always makes me comfortable and takes time to answer any questions, she is excellent.

> "Always very efficient and friendly which makes it a very relaxed atmosphere.

> "Getting IV is almost a relaxing experience.

> "Anne who gives me my treatment and advice etc is very kind, efficient and knowledgeable

> "It is most pleasant. The nurses particularly Ann can't do enough for you.

> "Staff are extremely welcoming making you feel at ease. Lovely.

This post has become an integral and essential part of the MS Service. We plan to continue auditing the effectiveness of this new role and hope to secure future funding to take it on permanently after the initial 3 years funding runs out.

MS Counsellor—MS Service, Douglas Grant Rehabilitation Centre, Ayrshire & Arran

Around half of all people with MS experience depression and a similar number suffer from anxiety, yet MS Society research shows that only half the people with MS (51%) who need mood or emotional support actually get it. NHS Ayrshire and Arran provides highly specialist clinical psychology service for those affected by MS. However, many people present with low levels of MS-related distress, requiring only short-term counselling interventions. Having alternative resources to meet these demands ensures that the clinical psychology service can offer higher levels of specialist intervention and neuropsychological assessment in a timely manner.

The MS Society Ayrshire and Arran wanted to explore ways to provide more responsive care and support to people affected by MS who are experiencing low mood or emotional problems. The primary objective of the service is to improve the mental health and well-being of the MS population in the area.

A MS Counsellor, Annette, was appointed and starting accepting referrals on 31 March 2015. The service is a one-to-one counselling service, funded and managed by the MS Society Ayrshire and Arran with support and steer from the MS team at NHS Ayrshire and Arran. The service is available to all people affected by MS in the Ayrshire and Arran area, and access to the service is not dependent on ability to pay. Those affected by MS can self refer or clients can be referred directly by a member of the clinical team at the Douglas Grant Rehab Unit.

The counsellor meets each referred client for an assessment appointment on their first visit, and may rebook for further interventions up to six times in total. If any client is deemed to require more than six interventions, it was agreed that Annette could extend the number of sessions to an individual if this was felt to be clinically appropriate. To date, with 36 referrals, a majority of clients have required fewer than six appointments. Several clients are receiving longer term support due to other difficult life events they have experienced since their counselling commenced. This is something Annette has become increasingly more aware of as we all experience bereavement, relationship problems, mental health issues, etc, but having to cope with MS in addition to this can be extremely difficult and can exacerbate MS symptoms.

Every client will complete an evaluation form on their final visit, and copies of these forms will be collated by the branch and form part of the final report. Clients are also given the opportunity for some wider feedback through a confidential interview process. We have had excellent feedback from clients and professionals who refer into the service. Some of the comments received:

> “Being able to have a conversation with a good understanding listener.

> “Being able to talk to someone to organise my thoughts and feelings over the phone.

> “…the caring and empathetic nature of the counsellor. I liked that Annette sent a letter confirming the first appointment, following a phone call.

The service initially ran on a one-year pilot basis, with quarterly steering group meetings, and continuous evaluation and a report being produced at 6 and 12 months. We are now going into year two of this development. The Ayrshire and Arran Branch (of the MS Society) continue to facilitate and fund this service.

7 Patient Reference Group

MS Specialist Physiotherapist

In the heady days following the decision to allow the use of DMTs in the Risk Sharing Scheme, Lothian put in place a consultant-led clinic at the Western General to carry out the required assessment of patients with MS who might benefit from receiving one of the new drugs. This starter clinic evolved into a "MS hub" with the presence of a MS Nurse Specialist and eventually a MS Specialist Physiotherapist. Having received diagnosis in 1998, when there was no treatment available other than admission to an acute ward and steroids, this new concept was like a breath of fresh air.

I was the third patient referred to our brand new MS Physio thus opening a new chapter in my MS journey. Not only was she attached to the clinic and therefore available for urgent treatment, but she began to hold fatigue management classes, Pilates, MS management classes and pain clinics, all of which were a world away from the desultory treatment we had been receiving. No longer did we have to wait for physiotherapy, we were seen (in emergency) on the same day, but normally within 48 hrs. No longer were we given "6 shots and you're out" whether your need was greater than that or not. MS is not like that: it does not fit into a nice convenient pattern, so urgent physio can make an enormous difference. I gained confidence and strength from Pilates classes, knowledge from management classes and most importantly, help and advice when floored by a relapse.

Our MS Physio sadly had an accident and had to reduce to part time—better than nothing. However, she finally decided to move away—calamity. We waited and trusted that there would be a new appointment, but we were wrong. There were stories of difficulty in finding someone to replace her and eventually we realised there was not going to be a physio attached to the clinic because "physiotherapy services were being rethought". We went in to bat with the MS Society to prove to hospital management how beneficial the post had been to patients with MS and what great value to the hospital the post was. It was obvious from the meetings I attended that we were going nowhere and the money would be used elsewhere.

The concept of an "MS hub" was now over and all these years later we are still without a MS Physio attached to the clinic. Patients often pay to go elsewhere to get the treatment they need. Physio services have been dispersed out "into the community" so we are back to waiting lists and limited availability. I suspect many patients with MS in Lothian just make do and deteriorate quietly like good patients without making a fuss. Just for a while, we had the semblance of a good, all-round MS clinic to help us in our battle but, in reality, it proved to be a bit of a mirage.

Sue Polson

8 The Allied Health Professionals Perspective

Following the interest in our entries in the 2014 National Report relating to 'Patient Stories' and 'The Nurses perspective' it was agreed this year to include an overview of the Allied Health Professionals perspective in relation to MS care in Scotland.

I have worked as a physiotherapist at the Douglas Grant Rehabilitation Unit in NHS Ayrshire and Arran for the past 21 years. In 2006 I took up post working only specifically with people with MS which was part funded by the MS Society and in 2009 I secured a permanent position as Consultant Physiotherapist in MS.

The MS service in Ayrshire and Arran has changed beyond recognition over this time. We have grown from a few hundred accessing our service to now having 1,000 people with MS registered with our service. The first Disease Modifying Therapy (DMT) drugs becoming available for people with MS in the '90s and I remember the political fight that followed to secure access and funding to these drugs which offered the first hope of altering the course of MS. We now have almost 350 patients receiving DMT's.

The consultant leading our service at the time, Dr Paul Mattison also really valued the contribution of the Multi Disciplinary team and throughout the noughties we sought every opportunity to build our team. We grew from a small team of 1 MS Nurse Specialist and a rehab consultant in 2000 to a team of 2 MS Nurse Specialists, 1 MS Support Nurse and a MS Specialist Occupational Therapist, Psychologist, Counsellor and myself in physiotherapy. We provide an area wide service across a large geographical area, which includes 2 islands. In addition to a small rehabilitation ward we are able to see people with MS in various clinics across the county and at home. Our service is self referral and as a team we review patients on an annual basis, monitoring physical and mental health over time. It has been a real privilege to see this team grow over the years becoming more autonomous in what we do, leading on innovation and research in MS and winning several awards for our service over the years. The MS service has been involved in a number of clinical drug trials. I have developed an interest in research and led on a number of research studies evaluating physiotherapy and exercise interventions. The most recent of these being 2 multi-centred studies: Web Based Physiotherapy for People with MS and the MS foot drop study which is comparing 2 treatments for foot drop, Functional Electrical Stimulation and Ankle Foot Orthosis.

As a physiotherapist my role is around the treatment of the physical manifestations of MS which include symptoms such as: fatigue, pain, spasticity, muscle weakness, tremor and inco-ordination, balance disorders and the impact these symptoms have on walking and daily activity. As a non medical prescriber I am able to advice and prescribe appropriate medications that go hand in hand with specific physiotherapy treatments and advice on posture, exercise and activity. Treatment should always be person centred and tailored to an individual's needs. My focus is to provide the knowledge and support which helps to build confidence and empower people with MS to find their own way to manage their condition and to lead the life that they aspire to lead.

9 Progress

Collection of data

Forms continue to be completed by the MS Nurse Specialists in NHS Boards and it has now been agreed that all (apart from one) NHS Boards will scan forms and email them to the central team. This will improve efficiency and security of transmission of data.

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

Dataset and definitions

A review of the SMSR dataset and definitions was undertaken in the latter part of 2015 and the new form and accompanying definitions were implemented on 1 January 2016.

Routine reporting

Distribution of Quarterly Reports to MS Nurse Specialists and Clinical Leads reflecting activity for the previous quarter and performance against national Neurological Standard 15.2 (2009) continues.

A review of the content and layout of the Quarterly Reports was undertaken in late 2015/early 2016 and has now been implemented with positive feedback from the MS Nurse Specialists.

SMSR National Meeting

Due to the success of the first SMSR National Meeting held September 2015 it has been agreed to hold a further meeting on 6 October 2016 at Stirling Court Hotel. Further information can be found on the SMSR website—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, NHS 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 coming 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 2017 SMSR Annual National Report.

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Appendix A List of Charts, Figures and Tables

Appendix B Feedback from Chief Executives

NHS Ayrshire & Arran

NHS Ayrshire & Arran has an estimated population of 370,600 and approximately 1,100 people with a diagnosis of MS being managed by the MS Team at the Douglas Grant Rehabilitation Centre. In 2015, 36 patients were diagnosed with MS, in line with previous years. The MS service is multidisciplinary involving MS Nurse Specialists, Allied Health Professionals and other services. The Neuro Rehabilitation Service has now appointed a non medical Clinical Lead to support the future service development through the MS Managed Clinical Network and wider Neuro Rehabilitation Services.

- There were continued challenges appointing a local neurologist with MS speciality that, along with other workforce challenges in general neurology was having an effect on waiting times. There is now a visiting Neurologist from the Queen Elizabeth University Hospital attending the NHS Ayrshire & Arran MS Service at the Douglas Grant Rehabilitation Unit 4 sessions per week. This will become permanent in the very near future.
- All the MS specific national standards continue to be met other than that contact made within 10 working days of diagnosis in 2015 was only 53%. However, there has consistently been a 100% achievement from date of receipt of referral. With the introduction of the MS Neurologist and involvement of other visiting Neurologists to both Ayr and Crosshouse Hospitals, we have already seen an improvement in the receipt of referral timescales.
- A MS Support Nurse has been recruited (supported by the Pharmaceutical Industry) to manage the increasing numbers of patients on IV disease modifying therapies. This post has brought a single and valued point of contact for the many patients, which makes it easier to recognise when a patient is less well, allowing early planning including infection screening, support and advice and onward referral to another member of the MS team. Having one to one support also allows patients time to be more open and honest about the issues affecting them. The MS Nurse Specialists now concentrate on new oral therapies for MS patients and providing specialist advice in the management of the disease.
- A one year pilot MS Counselling Service was established in partnership by MS Society Ayrshire and Arran Branch and MS Society Scotland, to provide short-term counselling interventions. Since March 2015, there have been 36 referrals. The service enables the clinical psychology service to offer higher levels of specialist intervention and neuropsychological assessment in a timely manner. In 2015 there were 36 referrals to the MS Counselling Service. The MS Society Ayrshire and Arran Branch have agreed that they will continue to fund this service subject to annual review.
- Research and Clinical trials continue to be an integral part of the MS Service in NHS Ayrshire & Arran. With a closer working relationship being established with the MS Service at the Queen Elizabeth Hospital it is also envisaged that there will be wider opportunities for participation in multi centre clinical trials.
- Education also remains a priority with awareness raising sessions and study days provided on a regular basis with Patient/Carers, non specialist Allied Health Professionals, nursing, paid carers including nursing/care home staff, peer support groups and local authority staff.

NHS Borders
Nil response received.

NHS Dumfries & Galloway
Nil response received.

NHS Fife
The Fife performance against the standards has been gradually improving. It is good to see the increasing percentage of patients being added to the Register. We are aware that we need to do further work on assessing the patients who have been referred within the standard. Our MS Clinical Nurse Specialist (CNS) was involved in providing an example of how the team used the Register to improve practice last year. She deputises for our clinical leads, Dr Spelmeyer and Dr Sloan at meetings if required.

NHS Fife is looking to improve the referral process further to reduce the delay from diagnosis by the neurologist to the patient being seen by our CNS. Our existing process means we are unlikely to meet the standard of contact within 10 working days so the team will pilot electronic referral to the CNS to assess if this is more effective and track progress through the quarterly returns

NHS Forth Valley
Neurological Standards

15.2 During a period in 2014/15, the MS Service in NHS Forth Valley experienced some staffing issues. In addition, during this period, the Board also saw an increase in the number of newly diagnosed patients with the highest level of referrals being received since the service began. Standard 15.2 was challenging to deliver on some occasions due to the above factors but, despite these issues, Forth Valley still outperformed the Scottish average in compliance of the standard.

14.1a/14.b Patients have access to a MS team consisting of one Consultant who specialises in the diagnosis and management of MS, one MS Nurse Specialist, one MS Nurse Specialist and one Secretary. Patients are referred based on individual need, to specialist neurorehabilitation services and other specialist services.

14.2a Newly diagnosed patients are referred promptly by neurologists and contacted by telephone within 10 working days of diagnosis, offered an initial appointment, usually within one week. Sessions are run on an individual basis, dependent on the needs of the patient; they are provided with a newly diagnosed pack and contact details. Newly diagnosed patients/families are invited to the annual “Getting to Grips” course which is run jointly with the MS service and the local MS society.

14.2b Ongoing needs are assessed on an individual basis. The MS service utilises our directory of locally available resources to promote self management, (i.e. Self management course run by the MS Society, Stress and Anxiety management courses, Pain Association Scotland, MS Society counselling services and others).

14.3 Training is organised with local care providers, and lectures are given regularly to student nurses at Stirling University.

15.1/15.2 Patients are referred to general neurology. If diagnosed with MS, they are then referred on to the MS service for discussion of treatment options.

15.3 CIS patients to be offered an appointment with MS Nurse Specialist and given a point of contact, these patients remain under care of their neurology consultant unless the diagnosis changes to MS.

16.1a Patients offered annual review at the Nurse led MS review clinic. New initiatives for the future include setting up telephone clinics and piloting clinics at health centres in rural Stirlingshire. House bound patients are offered a joint review with District Nurse if required or multidisciplinary team meetings are arranged with social work. Patients are referred to palliative care neurology Nurse Specialists as appropriate.

16.1b A help line operates Monday to Friday 8.30–4.30; call back usually within 24–48 hours.

16.2a Patients informed to contact the service with suspected relapse, assessed by a MS Nurse Specialist within 1–2 days in outpatients, home review for severe cases only, relapse management carried out as per protocol, steroids offered if appropriate, either oral or intra venous, liaise with GP, referred onto other multidisciplinary teams as required for rehabilitation.

16.2b Patients followed up at the MS Consultant clinic.

16.3 All patients with relapsing remitting MS who meet existing formulary guidelines are offered appropriate disease modifying therapies

NHS Grampian

The most recent data show that 83.0% of people with a new diagnosis of MS in Grampian were contacted by a MS Nurse Specialist within two weeks of confirmed diagnosis in 2014 and 82.5% in 2015. 98.1% in 2014 and 93.0% in 2015 of people with a new diagnosis of MS in Grampian were contacted by a MS Nurse Specialist within 10 working days of receipt of referral. No-one was recorded as waiting over two weeks from referral to first contact in Grampian in 2015. NHS Grampian has achieved above average standards. All the national neurological standards are reviewed annually in the department and we have largely exceeded or met those related to MS since their inception.

In the last year we have appointed another 0.8 W.T.E MS Nurse Specialist, expanding the MS nursing service to 1.9 W.T.E. This has allowed us to focus on developing and improving the service we offer to all those affected by MS in this region. We now have approximately 20 more clinic appointments per month.

We have also appointed a new consultant colleague who will share the development of the MS service. A new clinic for delivering disease modifying treatment has been set up.

NHS Greater Glasgow & Clyde

14.1 We provide patients with MS with access to a multidisciplinary team that specialises in the management of MS.

14.1b The MS multidisciplinary team consists of 5 consultants who specialise in the diagnosis and management of MS, 5 MS Clinical Nurses, the patient and the carer. Additional input from other healthcare professionals with experience and training in neurological conditions is offered from 2 MS Physiotherapists. Although not directly part of the Multi-disciplinary MS team we communicate closely with and have easy access to occupational therapy, speech and language therapy, dietetics, neurorehabilitation services, pharmacy services and mental health services.

14.2a At the moment we do not provide a group patient and family education programme for newly diagnosed MS patients. However, at the first MS Nurse Specialist clinic appointment patients and their family receive a lot of information about MS, including information about what the disease is and how it might affect them, available treatments and resources, and issues such as work, driving, insurance, vaccination and travel.

14.2b. At the moment we do not provide a group patient and family education programme to all MS patients. However, all MS patients are seen twice a year and can ask questions related to any aspect of their condition

14.3 At the moment we do not have a structured education programme that is specific to MS and offered to all healthcare professionals, who have regular contact with patients with MS. However, we regularly present updates on MS, at a weekly Neurology meeting, which is attended by all staff.

15.1 Patients referred with symptoms suggestive of central nervous system demylelination are offered investigations, and if undertaken, the results are explained and therapeutic options discussed with them.

15.3 Patients diagnosed with a clinically isolated syndrome are provided with information on how to access MS specialist services in the future.

16.1a Patients with MS are seen routinely by the MS specialist service every 6 months.

16.1b Patients with MS are given contact details for the MS service and have the opportunity to self-refer.

16.2a We do not yet have a relapse clinic but patients who develop new symptoms or worsening symptoms suggestive of a relapse are encouraged to contact the MS specialist service to discuss the problem and arrange acute management of the relapse and consider a possible switch in their disease modifying treatment. In many cases this involves early review in the out-patient clinic

16.2b Following the initial relapse assessment, a review is carried out by a member of the MS multidisciplinary team.

16.3 Patients with MS who meet the existing local formulary guidelines are offered specialised disease modifying drug therapies.

We are currently going through a redesign of the MS service in Glasgow. The aim of the redesign is to allow new patients, patients with active disease, patients who are not tolerating treatment, or are starting to progress from RRMS to secondary progressive MS or have some other issue they need to discuss with their consultant have rapid access to their MS Neurologist (within 2–4 weeks). While relapsing remitting patients who are clinically and radiologically stable and are tolerating their DMT's then they will be followed up by the MS Nurse Specialist.

NHS Highland

Nil response received.

NHS Lanarkshire

Data from the 2015 MS Register relating to the time from diagnosis to contact with a MS Nurse Specialist is accurate and shows that NHS Lanarkshire does not meet the standard. Most of the delay is accounted for by a delay in the MS Nurse Specialist receiving the referral. This is complicated due to patients being seen in Glasgow as well as in NHS Lanarkshire.

In response to the data all consultants now email the MS Nurse Specialist at time of diagnosis. Previously a letter was dictated, sent and delivered to the MS Nurse Specialist which resulted in an avoidable delay in the nurse seeing new patients. This has led to some improvement in our results, but exact figures are not available.

A neurologist with an interest in MS runs a weekly MS clinic and works closely with the MS Nurse Specialist to expedite MS Nurse Specialist review. Work is on-going with the MS Trust and local managers on options to improve the overall service to MS patients in Lanarkshire.

NHS Lothian

In the reporting period from 2014 until 2015 NHS Lothian has seen a 10% increase in the recorded numbers of people diagnosed with MS. In that period our services have delivered an 11% increase in the number of patients agreeing contact with a MS Nurse Specialist and receiving that first contact within 10 working days.

There are a number of reasons enabling this service level including:

- Increased use of electronic referral from MS Consultants to the specialist nurse service
- Use of voice recognition technology enabling streamlined and more efficient administrative processes
- Conclusion of a period of maternity leave enabling NHS Lothian MS Nurse Specialists to return to full capacity.

As noted within the statistics NHS Lothian has identified 1 outlying case record which indicates a delay of 196 days from diagnosis to first contact. On review we note that this reflected patient choice on this occasion as is indicative of the personal time which can be needed by individual patients following diagnosis before they are ready to engage with service support.

A MS pathway and service improvement plan is encapsulated within NHS Lothian's overarching Neurological Care Improvement Plan.

Recent work includes the development of a specialist team, supporting both inpatients and an outreach service for people with progressive neurological conditions, including MS. As part of a systems wide improvement this aims to deliver integrated multi disciplinary assessment and support on an individualised basis, with hospital admission supporting indepth clinical assessment where appropriate.

The multi-disciplinary team includes Consultant, MS Nurse Specialists AHP support including neurological physiotherapy and psychology, neuro-rehabilitation services, carer support and independent advocacy. It is the ambition of NHS Lothian, in partnership with Heath and Social Care Partnerships to continue to develop this service to ensure equity of access to all patients with progressive neurological conditions throughout Lothian.

NHS Orkney

4 Criterion 4.9

Together with a Community Occupational Therapist, the MS Advisor has run 3 MS Fatigue Self-management Groups (FACETS: Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle) since Spring 2015. This 6-week programme has been positively evaluated by all participants.

4 Criterion 4.12c

The MS Advisor has recently led a review of the local Anticipatory Care Plan (ACP). A new ACP has since been developed in collaboration with key stakeholders with the aim of being more person-centred; suitable for completion by service user and their family; suitable for use with patients with long term conditions, and for palliative care; aligned to the fields in the Key Information Summary (KIS), to allow the sharing of this important information with unscheduled care; and suitable for use across multi-agency sectors. The ACP is currently undergoing its second test of change, and has so far

been positively evaluated by health professionals and service users, several of whom have a diagnosis of MS.

1 Criterion 1.3

During the past year the MS Advisor has worked more closely with the local branch of the MS Society during a period of change and uncertainty for them. This collaborative working is ongoing, but so far has led to an increased awareness of the resources available both locally and nationally; instrumental to this has been the development of the 'MS In Orkney, Information Page' on Facebook.

NHS Shetland

Nil response received.

NHS Tayside

The SMSR annual report reflects the progress made and continues to be made within the MS service in NHS Tayside. The multidisciplinary team work in cohesive manner covering all aspects of patient care. The team is led by a consultant neurologist working in close collaboration with three MS Nurse Specialists who bridge the gap between primary and secondary care, a general practitioner, a MS study co-ordinator and, within the Dundee MS service, a MS Physiotherapist and MS Specialist Social Worker who is employed by the nearby City Council but works in close partnership with the NHS team. In 2015 the service was awarded the MS Trust QuDos award for Multidisciplinary team of the year. The QuDos awards highlight innovation and excellence in MS management and service delivery.

The service is performing well on important measures of patient satisfaction, measured using surveys developed in the GEMSS (Generating Evidence in MS Services) programme for the MS Nurse Specialists (MSNSs) service, the MS physiotherapy service and the MS social work service.

A number of priorities for development have been identified by the service including the possible recruitment of a support worker within the team to create more clinical capacity for the MSNSs, re-establishing and expanding patient group education, and making the case for specialist occupational therapy support for patients with MS.

NHS Western Isles

No newly diagnosed patients in the Western Isles 2014–2015

Contact is made by the MS Nurse Specialist as soon as the referral is received from Glasgow. This is usually within 10 working days of diagnosis but dependant on the correspondence being received from Glasgow within this timeframe.

14.1a Patients are referred and assessed on an individual basis with access to a MDT that specialises in the management of MS.

14.1b Patients with MS have access to:

Off Island

- A consultant who specialises in the diagnosis and management of MS.
- Neuro-rehabilitation PDRU + Raigmore

On Island

- MS Nurse Specialist
- Neuro Physio (Rehab)
- Neuro OT (Rehab)
- Speech and language services

- Diatetics
- Pharmacy services
- Mental Health Services

14.2a A Newly diagnosed group has been set up and is run annually

Patients, their families and or carers are continually supported, educated and seen as required on an individual needs basis.

14.2b Education programmes are tailored to fit within the individual patients and family and or carers needs and this support can be accessed throughout the course of their condition

14.3 Structured Information sessions specific to MS have been delivered to hospital and community staff AHP's, Social Work Home carers, and voluntary sector carers.

September 2016 MS Nurse Specialist Professional will be offered to all healthcare professionals that have regular contact with patients with MS.

15.1 Investigations are carried out in Glasgow. The results are usually given in Glasgow. Patients are supported during this process and after a definitive diagnosis is given.

15.2 As above

15.3 Patients with CIS their families/carers are supported and all have the contact details of The MS specialist nursing service.

16.1a Every patient with MS in the Western Isles are offered and annual review.

16.1b All patients with a definitive diagnosis of MS have the contact details of the MS specialist nursing service and have the opportunity to self-refer.

16.2a Patient with a suspected relapse have access to the MS specialist nursing service and are referred to the appropriated services as required.

16.2b A review is carried out by the MS service within 2 weeks following an initial relapse

16.3 All patients with MS who meet the existing local formulary guidelines are offered specialised disease modifying therapies.

The MS Nursing service applied and was accepted to participate in GEMSS II (Generating Evidence in MS Services). This was a flagship programme to collect evidence about how services work best for people with MS and develop NHS services for the future. The overall final report of this work, together with a report describing and evaluating the process, was published on 10 November 2015. This is available on the MS Trust website There is also a local report available specific to the service in the Western Isles.

Appendix C Organisational structure of SMSR

The Scottish MS Register is a national Register within the Scottish Healthcare Audits of the Information Services Division of NHS National Services Scotland. 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. See the SMSR website (www.msr.scot.nhs.uk) for details of the steering group.

The organisational structure of the SMSR is:

Dr Belinda Weller | Chair of the Steering Group

Chrissie Watters | National Clinical Coordinator

Derek Murphy | Information Analyst

Martin O'Neill | Principal Analyst

Funding is received from the Scottish Government for the central coordination of the SMSR. Each NHS Board is expected to continue to collect data for the SMSR. MS Nurse Specialists and others employed in each NHS Board collect the data for the Register. Staffing levels vary widely between hospitals. The responsibilities of those who collect the data 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.

Appendix D 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.

Previous Annual Reports.

Information on requesting SMSR data for research purposes.

Information on Quality Improvement and Neurological Standards.

Information for patients and carers.

Other useful links

The Scottish MS Register
www.isdscotland.org/Health-Topics/Scottish-Healthcare-Audits/Scottish-Multiple-Sclerosis-Register

ISD Scotland
www.isdscotland.org

Healthcare Improvement Scotland
www.healthcareimprovementscotland.org

MS Society
www.mssociety.org.uk

MS Society—What is MS?
www.mssociety.org.uk/what-is-ms/information-about-ms/about-ms

MS Trust—What is MS?
www.mstrust.org.uk/information/what-is-ms

Future MS
www.mssociety.org.uk/get-involved

future-ms.org

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 in the table below:

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

Notes:

* For information, please contact Moira Flett, MS Nurse Specialist.

** Diagnosis made by a General Neurologist from Institute of Neurological Science, Glasgow.

The MS Nurse Specialists who co-ordinate the work of the MS Register locally for each of the hospitals/ clinics are listed in the table below:

NHS Board	Hospital / Unit	MS Nurse
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Jacqueline Downs
Borders	Borders General Hospital	Lorna Rogerson
Dumfries & Galloway	Dumfries & Galloway Royal Infirmary	Elizabeth Clark
Fife	Cameron Hospital, Windygates	Debbie McCallion
Forth Valley	Forth Valley Royal Hospital	Madeleine Steele
Grampian	Aberdeen Royal Infirmary Dr Gray's Hospital, Elgin	Margaret-Ann MacLeod Gillian Alexander
Greater Glasgow & Clyde	Institute of Neurological Science, Queen Elizabeth University Hospital	Lynn Cherry
Highland	Raigmore Hospital Taynuilt Medical Practice, Connel	Anne Stewart Cheryl Howe
Lanarkshire	Greenhills Health Centre, East Kilbride	Mhairi Coutts
Lothian	Royal Infirmary of Edinburgh	Matthew Justin
Orkney	Balfour Hospital	Moira Flett
Shetland	Gilbert Bain Hospital	Elizabeth Clarke Dorothy Storey
Tayside	Ninewells Hospital	Pamela Walker
Western Isles	Stornoway Health Centre	Rachel Morrison

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

This report could not have been written without the help of a great many people. This includes:

- Patients with MS who have contributed medical information to the Register;
- Clinical, research staff at all hospitals/ clinics participating in the Register who ran their local data collection, provided local reports and commented on drafts of the National Report;
- NHS Board colleagues who provided feedback about changes that improved performance in delivery of care for MS patients;
- Patients who contribute to the Patient Reference Group and have contributed to this report;
- The SMSR central team and ISD Graphic Design Team as part of the Information Services Division of NHS National Services Scotland who co-ordinate and collate the necessary information to produce the report and support the publication of the National Report. In particular thanks to Chris Dunn and Joyce Dalgleish for your support and guidance; and
- Members of the Report Writing Sub-group of the SMSR Steering Group who have contributed to the writing of and commented on drafts of this report.

This annual National Report was prepared by Hazel Dodds, Jacqui Downs, Debbie McCallion, George Mowat-Brown, Derek Murphy, Martin O'Neill, Dr Jonathan O'Riordan, Chrissie Watters and Dr Belinda Weller with contributions from NHS Boards.

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

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

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Scottish
MS Register