



**Scottish Multiple
Sclerosis Register.**

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ISD Scotland Publications

Information Services Division
NHS National Services Scotland
Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB

phone: +44 (0)131 275 6233

email: NSS.PHIgraphics@nhs.net

Designed and typeset by:
Chris Dunn, PHI Graphics Team

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Foreword



Safe, effective, person-centred care for people living with Multiple Sclerosis (MS) remains a key priority for NHS Scotland and Scottish Government. We are committed to driving forward improvements in this area to ensure that everyone living in Scotland with MS can access the best possible care and support.

To this end, we greatly appreciate the insight which the Scottish Multiple Sclerosis Register (SMSR) data provides. The SMSR has proved to be an invaluable tool, not only in enhancing our epidemiological understanding of MS, but also in improving standards of treatment throughout the country. Crucially, it helps us to identify where we must do more to raise the standards of care in Scotland.

I was pleased to note that this year there has been a further increase in the percentage of newly-diagnosed patients receiving contact from an MS specialist nurse within 10 days of initial referral. This has increased from 61.6% in 2015 to 65.3% in 2016. Whilst this is a step in the right direction, we know there is more work to be done on this measure.

Data also show that from the point when an MS specialist nurse receives the referral, 93% of patients were contacted within 10 working days of diagnosis. This is testament to the hard work of MS specialist nurses across the country and we will continue to support them, locally and nationally, to drive further improvements in care.

On behalf of the Scottish Government, I want to offer my thanks to the teams involved – both clinical and analytical - who make the production of this report possible. It is only with their sustained support, enthusiasm and commitment that the SMSR can continue to raise the standards of treatment and care for people who live with MS.

Dr Catherine Calderwood
Chief Medical Officer

1 Introduction

It gives me great pleasure to introduce the seventh annual report of the Scottish Multiple Sclerosis Register. The register has been collecting data related to new diagnoses of MS since 2010. To date data have been collected for 3243 cases with a verified diagnosis of MS. The register relies on the ongoing support of MS specialist nurses, neurologists and rehabilitation consultants, Allied Health Professionals and managers who submit data on people with a confirmed diagnosis of MS using a standard paper based proforma. The data are stored within the Information Services Division (ISD) of National Services Scotland (NSS) and are analysed to explore epidemiological trends in MS and also to audit availability and access to MS services throughout Scotland.

The register is overseen by a steering group consisting of MS Neurologists, MS specialist nurses, AHPs and patient representatives, along with representatives from the MS Society and the MS Trust. The steering group works with staff from ISD who coordinate the register nationally and who collate and validate the results.

An important development over the last year has been the introduction of case note validation of reported cases. This will ensure a standardised high quality of data provision and will ensure accuracy of inclusion of the MS diagnosis. This will enable more accurate reporting of national and local incidence rates and help with future prevalence ascertainment.

Data from the SMSR have been presented at national and international meetings with oral presentations at the Scottish Association of Neurological Sciences (SANS) meeting in 2016 and at the European Committee for Treatment and Research in MS (ECTRIMS). A national register meeting was held in Stirling on October 6th 2016 and was well attended by health professionals, patient representatives and managers interested in MS from all over Scotland.

As well as exploring epidemiological trends in MS and giving up to date incidence rates of MS in different Scottish regions, data have been used to highlight inequalities of specialist nursing provision for people with MS. NHS Lanarkshire continue to have inadequate specialist nursing provision for its large MS case load. Similarly NHS Lothian has two full time MS specialist nurses for a case load of over 2200 which greatly exceeds the MS Trust recommended case load for MS specialist nurses. Information related to prescribing of disease modifying treatments (DMTs) has been collected and will be used to ensure that access to all Scottish Medicines Consortium (SMC) approved treatments is equitable.

The National Advisory Committee for Neurological Conditions (NACNC) at the Scottish Government has highlighted the need to establish prevalence figures for common neurological conditions such as MS. It is hoped that the SMSR can work closely with the NACNC MS subgroup to improve collection of prevalence data, however this will be dependent on available resources as the SMSR was originally set up to collect incidence data only.

Prevalence data for MS already exists in a number of regions but where this has not been done we will aim to develop methods to integrate General Practice records, hospital attendances and prescribing information, along with existing databases to give an accurate prevalence estimate for MS in Scotland.

I would like to thank Stuart Baird and Hazel Dodds at NSS for their continued input to the register. In particular thanks to Chrissie Watters who is our clinical coordinator who has regularly visited all of us involved in data submission to ensure our continued commitment and enthusiasm. Thanks also to George Mowat-Brown who chairs the patient representative group (PRG) and provides feedback from this group to the steering group. The input from Geraldine Mynors from the MS Trust (who has recently left this role) and Rebecca Duff from the MS Society has always been thoughtful and appreciated.

In particular I wish to thank the MS specialist nurses who continue to input data for the register. As we continue with budgetary constraint in the NHS everyone is facing increasing demands on their time and energy. None the less it is more important than ever that we continue to collect accurate data relating to MS diagnoses and services. This information will help us to develop practical solutions to improve provision of care to people with MS living in Scotland. It is also important that we use this information to recognise the incredible high quality service that many individuals and institutions are already providing.

Dr. Belinda Weller

National Clinical Lead, SMSR
Neurologist
Chair SMSR Steering Group

1.1 This report

This year's report presents data for 2016 for Scotland overall and for each individual hospital/ unit managing MS patients in Scotland. The data represents patients who were newly diagnosed with MS in Scotland in 2016.

In summary, there were 490 patients newly diagnosed with MS in Scotland in 2016 and 487 receiving support from the MS specialist nursing service. Every effort has been made by the central team and the MS specialist nurses to improve case ascertainment and provide a true reflection of incidence of MS in Scotland in 2016 though it is acknowledged that some cases may not have been added to the SMSR for various reasons.

Throughout 2016 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, Health Board and individual hospital data are displayed in charts and tables throughout the report.

1.2 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. Within the report a member of the Patient Reference Group shares an interesting perspective of their experience from diagnosis, NHS Fife describe how they have made innovative changes to practice leading to improvement in delivery of care for MS patients and NHS Ayrshire & Arran share the latest research studies from physiotherapy.

1.3 How MS data are collected

The SMSR central team and the MS specialist nurses have increasingly cross checked the centrally held SMSR data with routinely collected local data. Continuing to improve the systems and processes to validate data will lead to more robust case ascertainment and clearer incidence reporting of MS in Scotland.

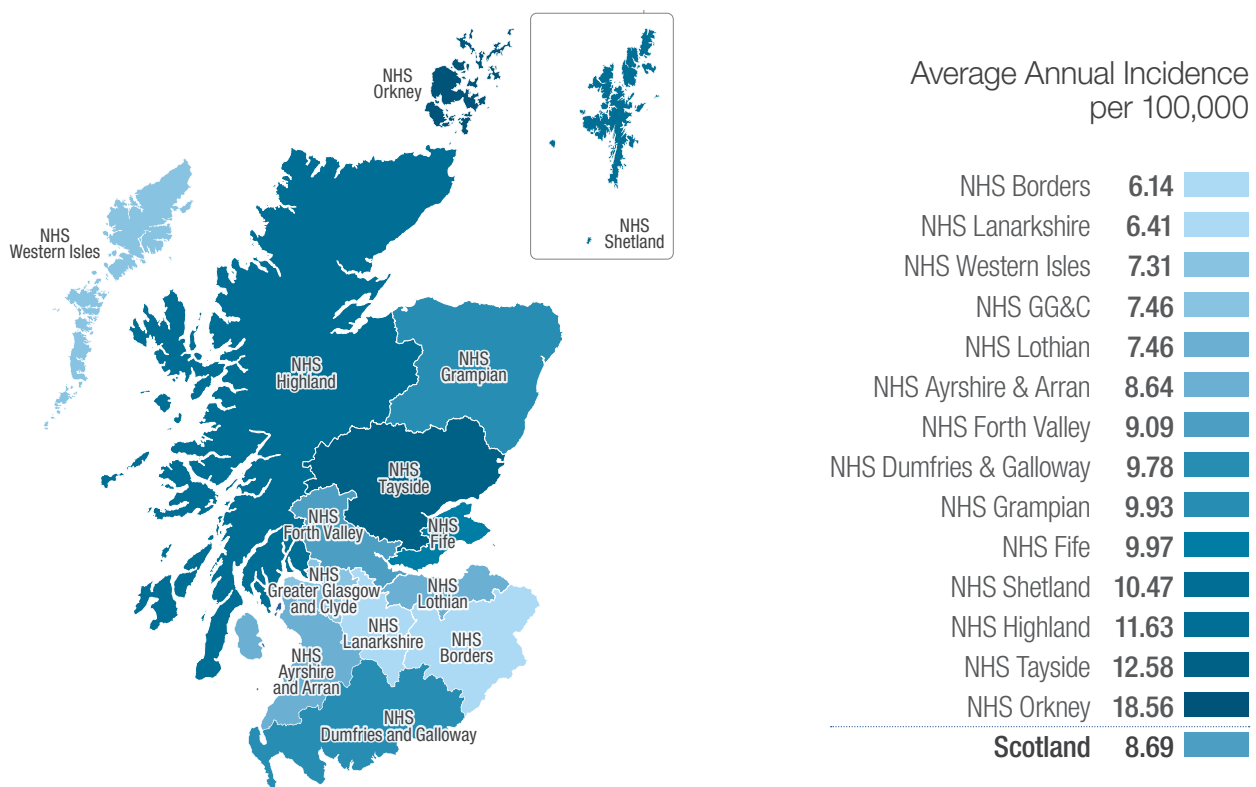
Strenuous efforts have been made to maximise data capture for all variables in all Health Boards however, it should be noted that some data are incomplete. This being the case, results presented within this report should be used for indicative purposes only and should be interpreted with caution. The notes below each table/ chart highlight any particular areas of data incompleteness known to the team.

2 Overview of 2016

All of the Health Boards in Scotland have contributed to the data since 2010. The number of recorded new cases of MS in Scotland was 490 this year which is lower than last year. It is difficult to know whether this reflects a normal fluctuation in MS incidence or whether there has been a decrease in case ascertainment. Although the number of reported cases is down this year from the 546 cases reported last year, there has been a general upward trend in the number of reported cases since the register began.

The overall annual incidence per 100,000 population in Scotland is 8.6 with the highest incidence rate of 18.56 recorded in Orkney and the lowest incidence rate of 6.14 in NHS Borders. Despite the lower number of incident cases this year the overall rate remains similar to last years rate. This remains lower than the previously reported incidence rate for Scotland of 12.2/1000 (Rothwell² et al 1988). This is a reflection of several factors; firstly cases recorded in the SMSR have a diagnosis of MS confirmed by strict criteria (McDonald³, 2010) and do not include cases of clinically isolated syndrome or “possible or probable MS”. The register also does not as yet collect data for paediatric cases of MS although this is to be considered in the near future.

Figure 1 Average annual incidence of patients newly diagnosed with MS per 100,000 population, 2010–2016 data (by Health Board).



Notes:

- 1 Darker colours indicate a greater average annual incidence per 100,000.
- 2 Average (mean) population estimates across the 7 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.
- 3 The average annual incidence of MS per 100,000 population across the 7 year time period is calculated using mean mid-year population figures and the mean annual number of newly-diagnosed patients residing in each Health Board.
- 4 Cases with incomplete/missing date of confirmed diagnosis (N = 7) have been excluded from the data presented in this chart.

2.1 Results and Main Findings

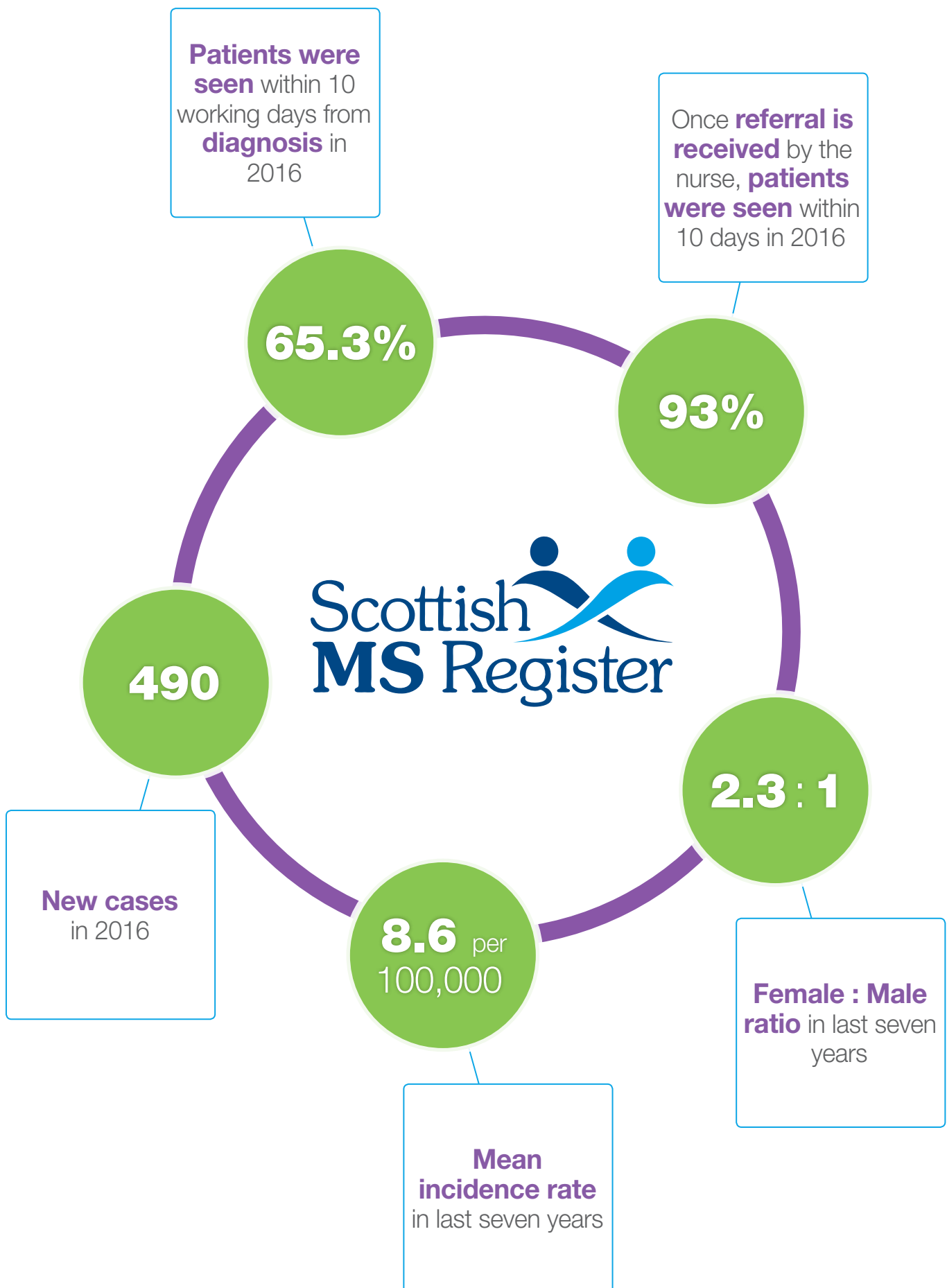
The female to male ratio of newly diagnosed cases of MS has remained stable at 2.3:1 with overall incidence figures of 5.4 per 100,000 for males and 11.7 per 100,000 for females. Our data do not reflect the trend for an increase in the female to male ratio reported in other parts of the world.

The SMSR continues to audit rates of and time to contact with an MS specialist nurse after a diagnosis of MS. The percentage of cases meeting the national clinical standard¹ 15.2 (which states “Contact with an MS Clinical Nurse Specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of diagnosis”) has increased from just over 60% in 2015 to 65.3% this year which is very pleasing.

Importantly, once the MS specialist nurses have received a referral for a new diagnosis of MS, 93.3% of cases are seen within 10 working days. This is an exceptional result and also reflects improvement from last year.

The delay in contact therefore is caused by slowness of the initial referral to the MS specialist nurse. This is most likely to happen where diagnoses are made in locations remote from MS clinics. General neurologists involved in the diagnosis of MS need to be reminded of this standard. They should be reminded that MS specialist nurses should be informed promptly (via email, telephone or in person) of each new diagnosis. This is also important to ensure that all diagnosed cases have the opportunity to be included in research such as Future MS which is focussed on new cases of MS.

Figure 2 Summary of key facts



3 Neurological Standards (2009)

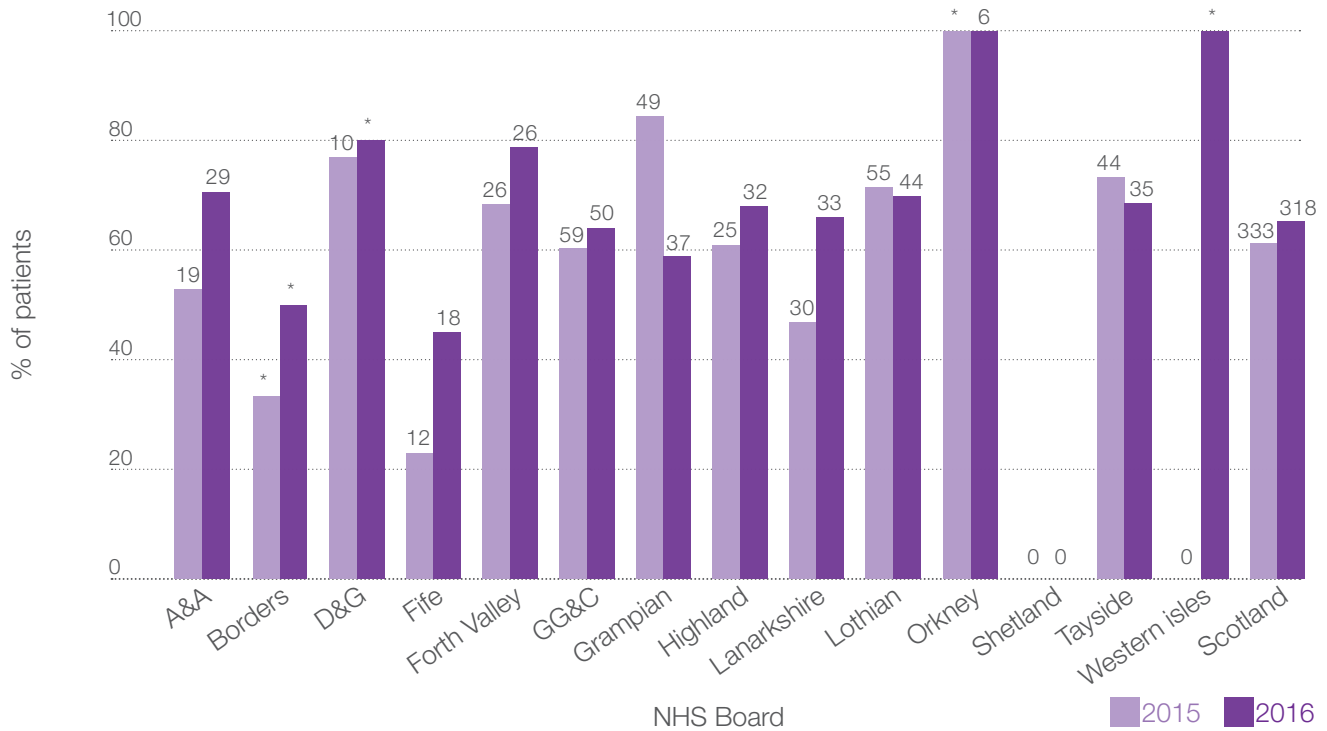
Standard 15.2 of the Clinical Standards for Neurological Health Services (2009) states that following a diagnosis of multiple sclerosis: “Contact with a Clinical Nurse Specialist is offered at diagnosis to patients with MS and contact is made within 10 working days of diagnosis”.

65.3% of patients had contact from the MS specialist nurse within working 10 days following confirmed diagnosis.

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

Chart 1 illustrates that the majority of patients diagnosed in Scotland are contacted by an MS specialist nurse within 10 working days, but there remains considerable variation across Scotland and room for improvement. A major limiting factor appears to be the time it takes to inform the MS specialist nurse, as illustrated by subsequent charts and figures.

Chart 1 Percentage and number of people with a new diagnosis of MS contacted by an MS specialist nurse within 10 working days of confirmed diagnosis, **2015 and 2016 data**



Notes:

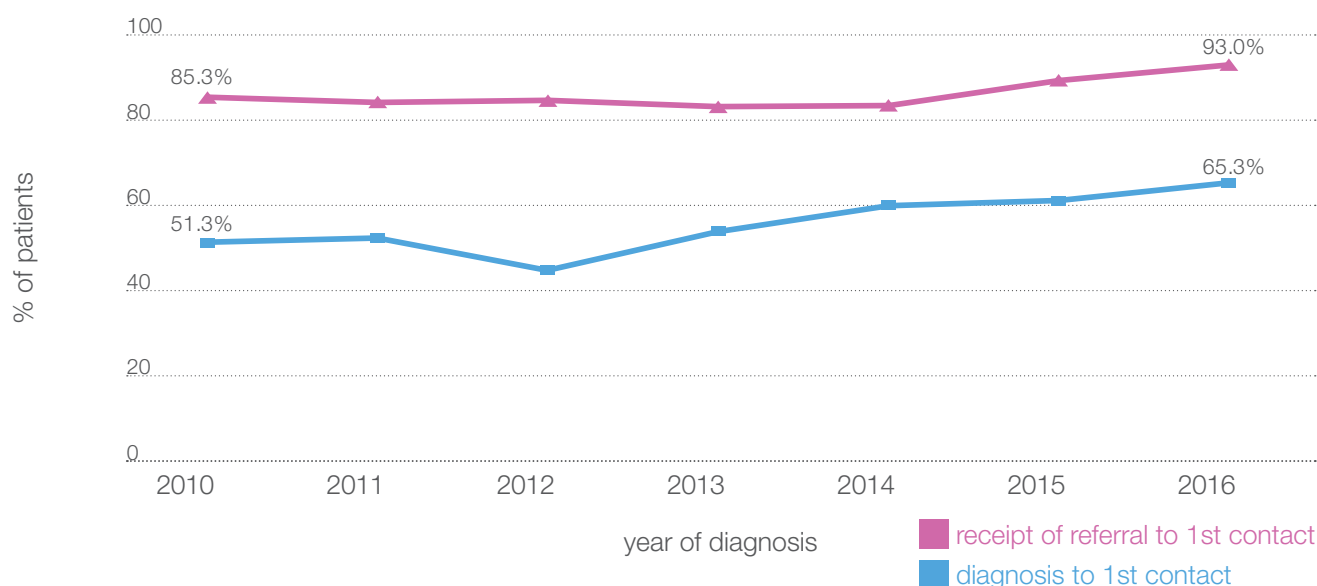
- 1 Cases for which contact with an MS specialist nurse was declined (N = 3) have been excluded.
 - 2 Data for this chart are based on Health Board of residence. Consequently, this may not be an accurate representation of each Health Board's performance as some patients may have chosen to be treated under a Health Board area other than that in which they reside.
 - 3 No new diagnoses of MS were reported in NHS Western Isles in 2015.
 - 4 No new diagnoses of MS were reported in NHS Shetland in 2015. Patients diagnosed in 2016 were not seen within 10 working days 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.

65.3% of patients had contact from the MS specialist nurse within working 10 days following confirmed diagnosis compared to **93%** once the nurse had received the referral.

Neurological Standard: Contact with an 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 trends towards gradual improvement are evident in both measures, which is reassuring, and in 2016 93% of people diagnosed with MS received contact from an MS specialist nurse within 10 working days of that nurse becoming aware of them. To improve performance against this standard the people who actually diagnose MS (Neurologists) need to work harder to inform the MS specialist nurse of those people diagnosed with MS in a timely manner and clinical teams need to ensure that robust communication processes are in place, so that contact and support can be offered as soon as possible following diagnosis - currently only 65% are contacted by an MS specialist nurse within 10 days of receiving a diagnosis.

Chart 2 Percentage of people with a new diagnosis of MS contacted by an MS specialist nurse within 10 days of confirmed diagnosis Vs percentage contacted within 10 days from receipt of referral, **2010–2016 data**

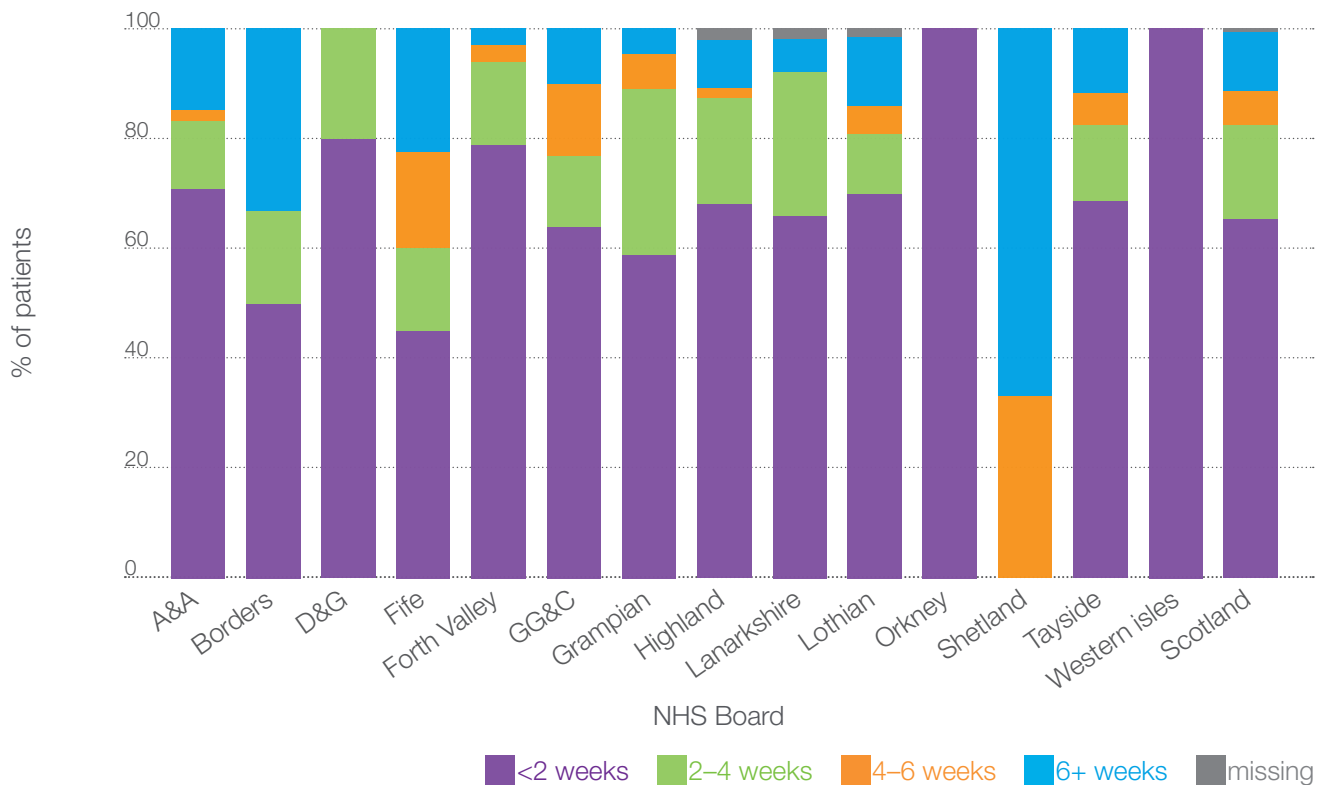


Notes:

- 1 Cases for which contact with an MS specialist nurse was declined (N = 3) have been excluded from the data presented in this chart.
- 2 Cases with incomplete/missing date of confirmed diagnosis (N = 9) have been excluded from the data presented in this chart.

Chart 3 shows the time between confirmed diagnosis of MS and initial contact with an MS specialist nurse. Across Scotland 65.3% of people with MS are contacted within 10 working days of a confirmed diagnosis. Unfortunately this target is missed within 34.7% of cases. A great degree of variation is seen between Health Board areas and this is indicative of the range of systems and processes of referral within Health Boards. Delays in referral are reduced or omitted in centres where designated MS clinics are undertaken and MS specialist nurses are available immediately following confirmed diagnosis.

Chart 3 Percentage of people newly diagnosed with MS in Scotland, by number of weeks from confirmed diagnosis to first contact with an MS specialist nurse, 2016 data



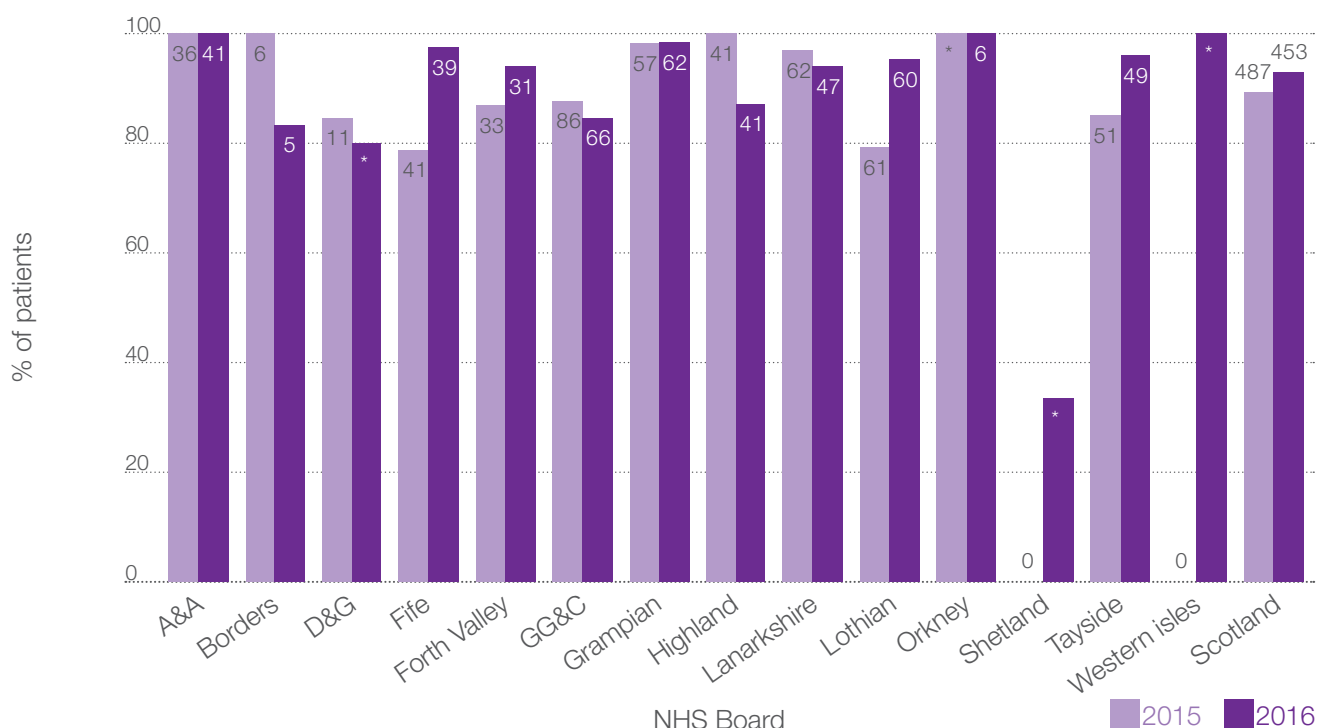
Notes:

- 1 Cases for which contact with an MS specialist nurse was declined (N = 3) have been excluded.
- 2 Data for this chart are based on Health Board of residence. Consequently, the above may not be an accurate representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a Health Board area other than that in which they reside.
- 3 'Missing' indicates a missing/incomplete date of first contact with an MS specialist nurse.

93% of patients had contact from the MS specialist nurse within 10 working days of receipt of referral.

Chart 4 illustrates that 93% of patients had contact from an MS specialist nurse within 10 working days of receipt of referral in 2016. This is a 4% improvement from 2015. Of the 487 newly diagnosed patients with MS in Scotland 93% were contacted within ten days of the referral being received. NHS Fife shows an improvement from 78.8% in 2015 to 97.5% in 2016 which may be attributed to the investment of additional MS specialist nurses. In comparison NHS Greater Glasgow & Clyde also invested in additional specialist nurse resources though this resulted in a slight decrease from 87.8% in 2015 to 84.6% in 2016. This indicates that MS specialist nurse resources are not the only variable and processes should be explored further to make improvement. Only 3 patients declined contact with an MS specialist nurse and have been excluded from this analysis.

Chart 4 Percentage of people with a new diagnosis of MS contacted by an MS specialist nurse within 10 days of receipt of referral, **2015 and 2016 data**

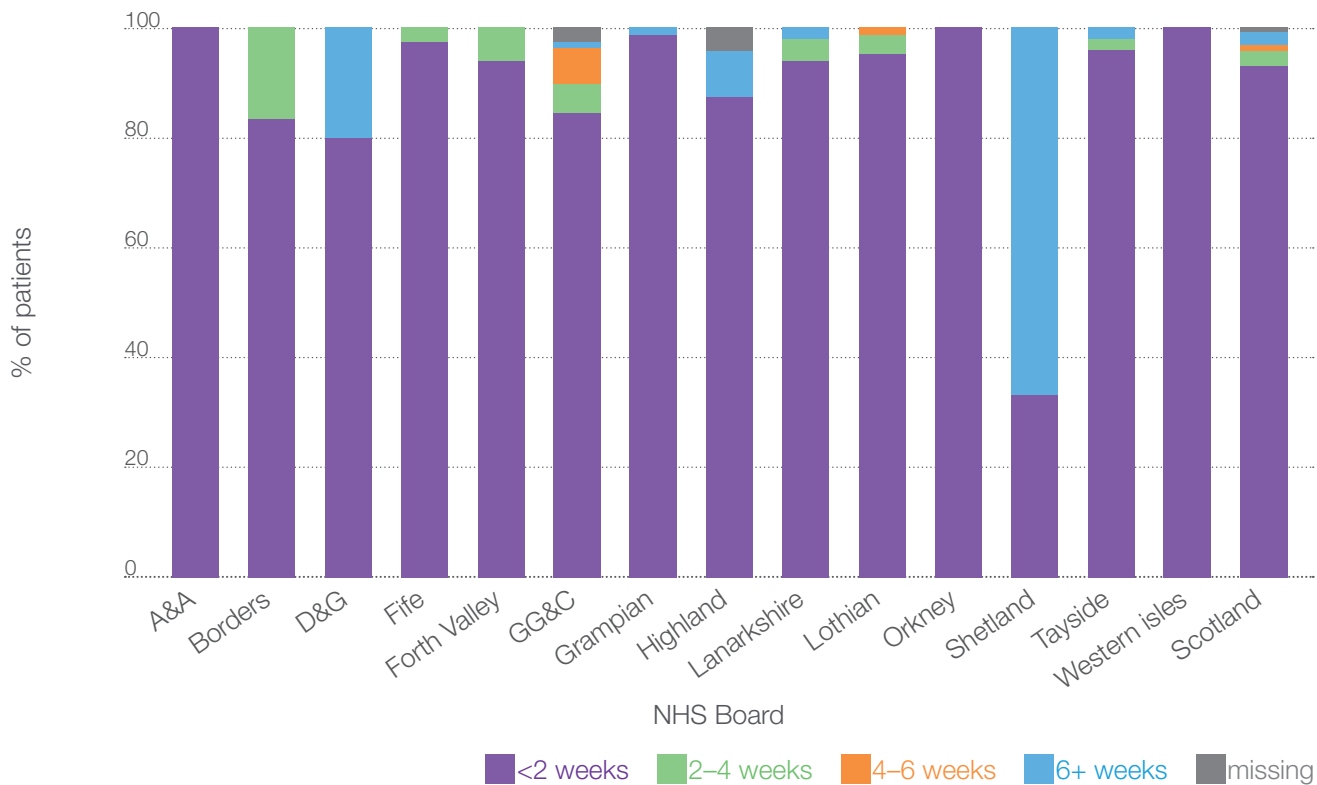


Notes:

- 1 Cases for which contact with an MS specialist nurse was declined (N = 3) have been excluded.
 - 2 Data for this chart are based on Health Board of residence. Consequently, this may not be an accurate representation of each Health Board's performance as some patients may have chosen to be treated under a Health Board area other than that in which they reside.
 - 3 No new diagnoses of MS were reported in NHS Western Isles in 2015.
 - 4 No new diagnoses of MS were reported in NHS Shetland for 2015.
- * 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.

Chart 5 shows time taken from receipt of referral by an MS specialist nurse to first contact, which is within 10 working days 93% of the time. This continues to show an improvement of 4% as shown in the data from the last 2 years. NHS Ayrshire & Arran continue to achieve 100% this may reflect the investment in resources highlighted in the 2015 SMSR Annual Report and commented on by the Chief Executive Officer within this report. Fewer Health Boards have submitted incomplete data compared to 2015. The SMSR aims to reduce the submission of incomplete data with the introduction of an electronic incidence recording form which one health board will pilot in 2017.

Chart 5 Percentage of people newly diagnosed with MS in Scotland, by number of weeks from receipt of referral to first contact with an MS specialist nurse, **2016 data**



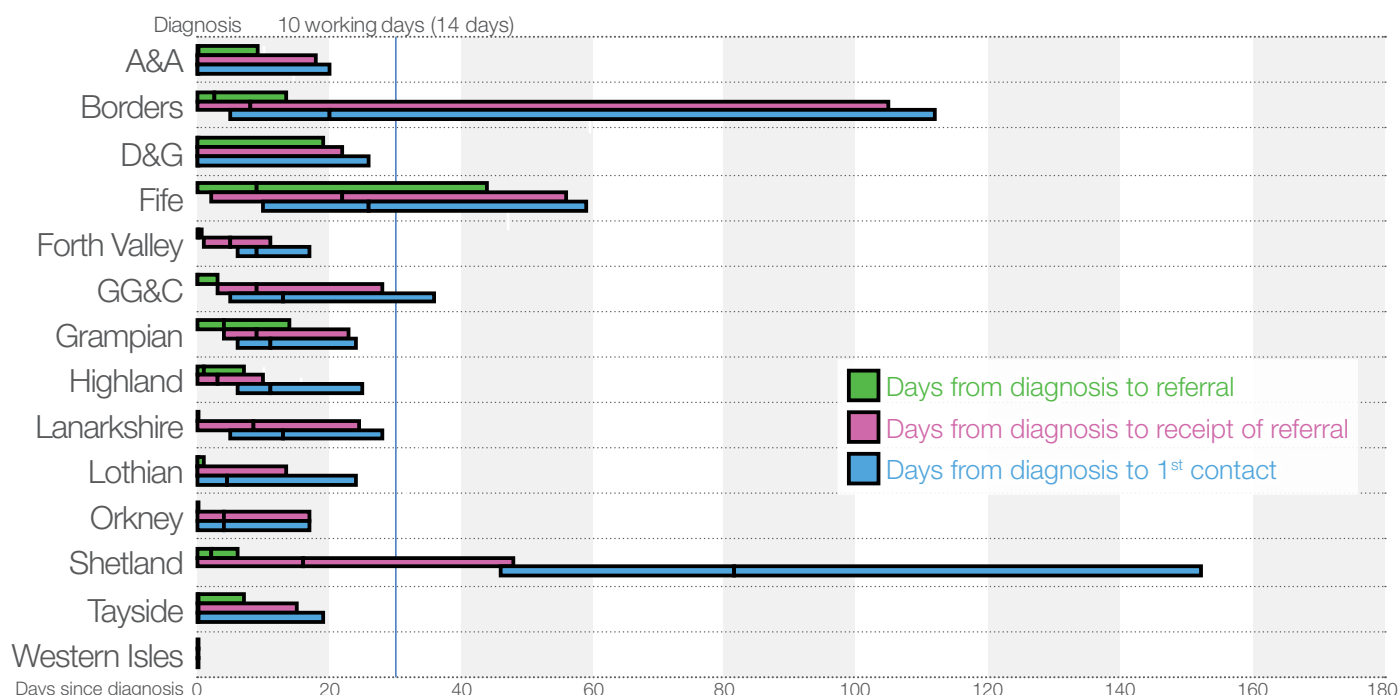
Notes:

- 1 Cases for which contact with an MS specialist nurse was declined (N = 3) have been excluded.
- 2 Data for this chart are based on Health Board of residence. Consequently, the above may not be an accurate representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a Health Board area other than that in which they reside.

Chart 6 represents the time taken for each stage of the referral process after a diagnosis of MS is made. This chart confirms variation in practice, clinic arrangements and diagnostic processes in different centres across Scotland. In centres where diagnosis is made in a designated MS clinic a referral is often made to the MS specialist nurse at the time of diagnosis and the patient may have the chance to meet the nurse as soon as the diagnosis is made. In other centres, patients may be diagnosed in one Health Board but be resident in another Health Board, this could result in delays in the referral process. This is demonstrated in Figure 3 of the report.

Across Scotland there is still delay demonstrated between the diagnosis and receipt of referral by the MS specialist nurse and ways to expedite this continue to be explored. However, as outlined in charts 4 & 5, the majority of patients will be contacted within the required standard of 10 working days.

Chart 6 Distribution of the number days between each stage in the referral process from diagnosis to first contact by a MS nurse, **2016 data** (by Health Board, reporting on all patients with a new diagnosis of MS)

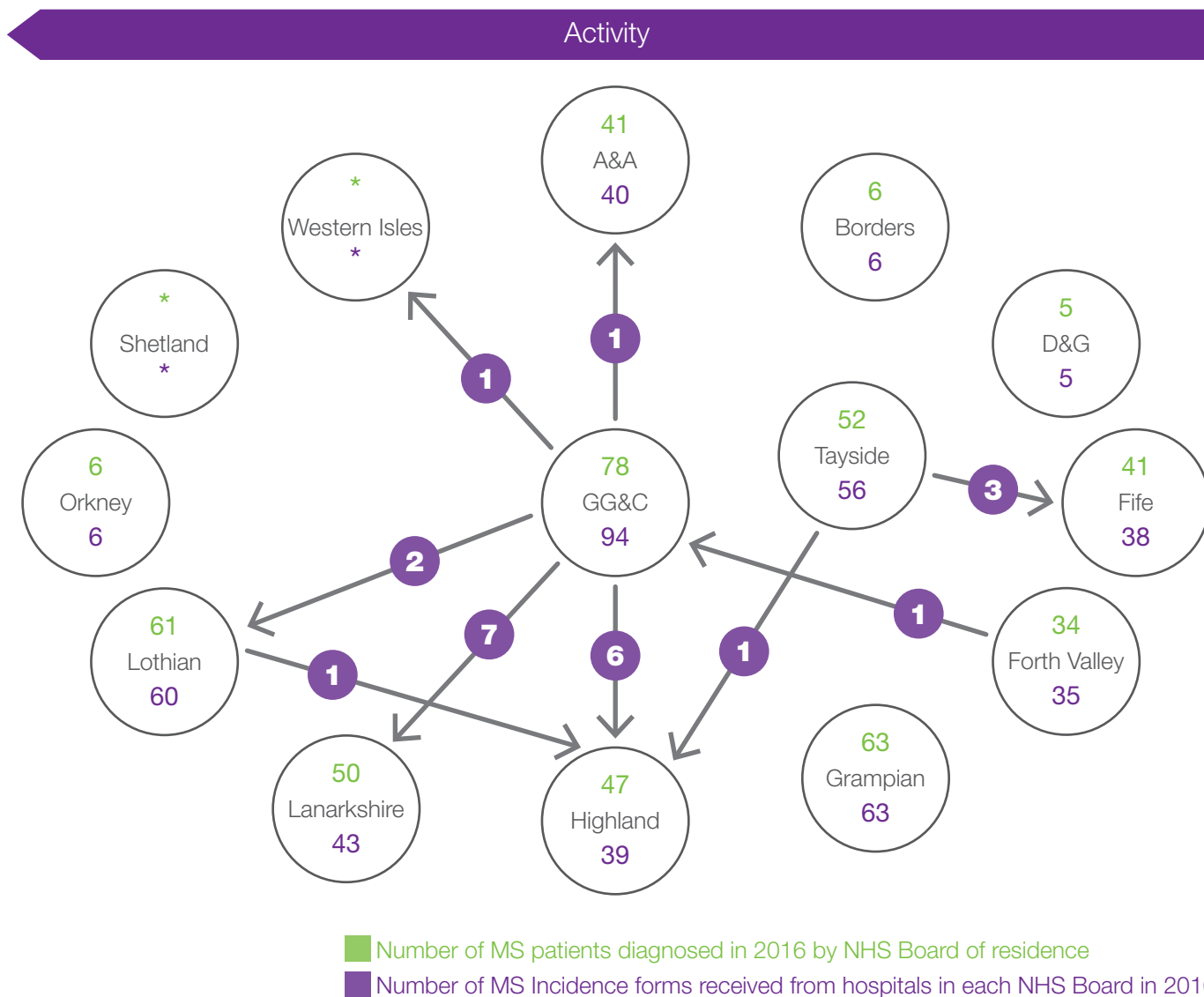


Notes:

- 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 2016. 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 NHS Tayside had their referral sent to an MS specialist nurse, that the MS specialist nurse received the referral, and that the patient had their first contact with the MS specialist nurse 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 an MS specialist nurse between 0 and 8 days following diagnosis, the MS specialist nurse received the referral between 0 and 17 days following diagnosis, and the patient had their first contact with the MS specialist nurse between 0 and 20 days following diagnosis.
- 3 Cases for which contact occurred or the referral was sent or received prior to diagnosis (N = 41) have been excluded.
- 4 Data for this chart are based on Health Board of residence. Consequently, the above may not be an accurate representation of each Health Board's performance as it is possible that a proportion of patients will choose to be treated under a Health Board area other than that in which they reside.

Figure 3 Activity diagram – Number of patients with a new diagnosis of MS by Health Board where diagnosed Vs Health Board of residency at time of diagnosis, **2016 data**

Figure 3 demonstrates that clinics in NHS Greater Glasgow & Clyde tend to diagnose people from a number of surrounding areas, whereas NHS Fife, Forth Valley, Lothian, Grampian and Tayside diagnose almost nobody living outside that area. Similarly diagnosis occurs in NHS Greater Glasgow & Clyde (GG&C) for a number of people who go on to see their MS specialist nurse and access local services in a neighbouring Health Board.



Notes:

- 1 The purpose of this figure is to illustrate cross border activity between Health Boards.
- 2 This figure illustrates, for example, that 78 newly diagnosed people in 2016 were resident in the NHS GG&C area, while 94 patients were diagnosed at a participating hospital under NHS GG&C in 2016. 6 of the patients diagnosed at NHS GG&C were resident in the NHS Highlands area; 7 were resident in the NHS Lanarkshire area; 2 in the NHS Lothian area; and 1 each in the NHS Ayrshire & Arran and NHS Western Isles areas. One patient diagnosed by NHS Forth Valley in 2016 was resident in the NHS GG&C area ($94 - 6 - 7 - 2 - 1 - 1 + 1 = 78$).
- 3 Cases where the hospital the incidence form was received from were blank (N = 2) were excluded from the data presented here.

3.1 Demographics

A total of **3,243** people have been diagnosed with MS and reported to the Scottish MS Register from 1st Jan 2010 to 31st Dec 2016.

The number diagnosed has decreased from **530** in 2015 to **490** in 2016.

490 newly diagnosed cases of MS were reported to the Scottish MS Register in 2016, which demonstrates consistency in incidence reporting with the exception of 2015 which was the highest number since the Register was started in 2010. There is continuous work nationally to improve case ascertainment and 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 national clinical standards of care are to be met.

Table 1 shows the reported incidence of MS by Health Board of residence. Data demonstrated here indicate that although there has not been much variance of annual incidence reporting from 2010 nationally both NHS Ayrshire & Arran and NHS Forth Valley have shown a vast increase. As discussed within this and previous reports MS teams are developing processes to improve case ascertainment which may reflect in increased reporting.

Table 1 Number of people with a new diagnosis of MS in Scotland, **2010–2016 data**, reported by Health Board of residence

NHS Board	Year of Diagnosis							
	2010	2011	2012	2013	2014	2015	2016	
NHS Ayrshire & Arran	17	28	34	36	33	36	41	
NHS Borders	8	7	7	7	7	7	6	
NHS Dumfries & Galloway	12	16	15	25	17	13	5	
NHS Fife	28	28	33	40	34	52	41	
NHS Forth Valley	17	23	25	26	28	38	34	
NHS Grampian	54	49	61	64	53	58	63	
NHS Greater Glasgow & Clyde	94	83	83	83	77	98	78	
NHS Highland	36	23	30	39	45	41	47	
NHS Lanarkshire	48	30	46	29	26	64	50	
NHS Lothian	60	54	50	74	67	77	63	
NHS Orkney	5	*	5	*	*	*	6	
NHS Shetland	*	6	*	*	*	*	*	
NHS Tayside	42	42	57	51	59	60	52	
NHS Western Isles	*	*	*	*	0	*	*	
Total	430	396	450	481	450	546	490	

Note:

- 1 3 patients, residing under the NHS Greater Glasgow & Clyde (2) and NHS Fife (1) Board areas, 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.

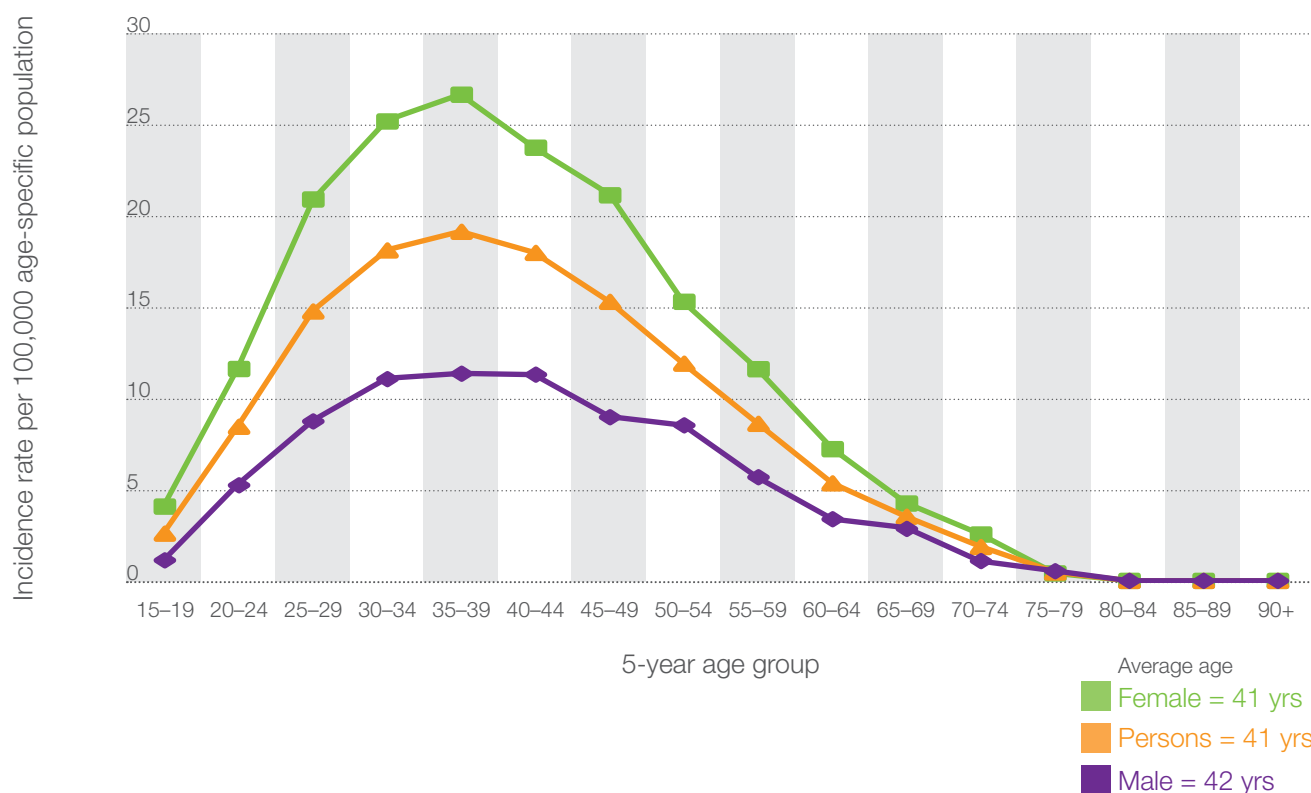
The mean age of diagnosis is **41** years old.

Chart 7 describes the average age of people newly diagnosed with MS in Scotland. At present this is 41 years for women and 42 years for men. Overall, the average age at diagnosis is 41 years. The average age at diagnosis suggested by these data may be a bit higher than reality as the register does not capture the small number of paediatric MS cases seen in children below the age of 16 years.

It is interesting to note that people continue to be diagnosed with MS in Scotland in the 75 to 79 age range. We may be diagnosing patients at older ages in areas where access to neurological services has been historically poor. Unfortunately we do not have individual patient details that would let us know if earlier opportunities to make a diagnosis had been missed. It is also possible that a diagnosis of MS is less likely to be considered in an older person. The incidence of MS being diagnosed at an older age may decline in the future with better access to neurological services and magnetic resonance imaging (MRI) scanners.

Overall the 7 year average annual incidence of MS in Scotland is 8.6 per 100,000 of population per year based on data available to the register. Broken down by gender we see 11.7 women and 5.4 men with MS per 100,000 of population per year.

Chart 7 Average annual age specific incidence of people newly diagnosed with MS in Scotland per 100,000 population, 2010–2016 data (by gender)



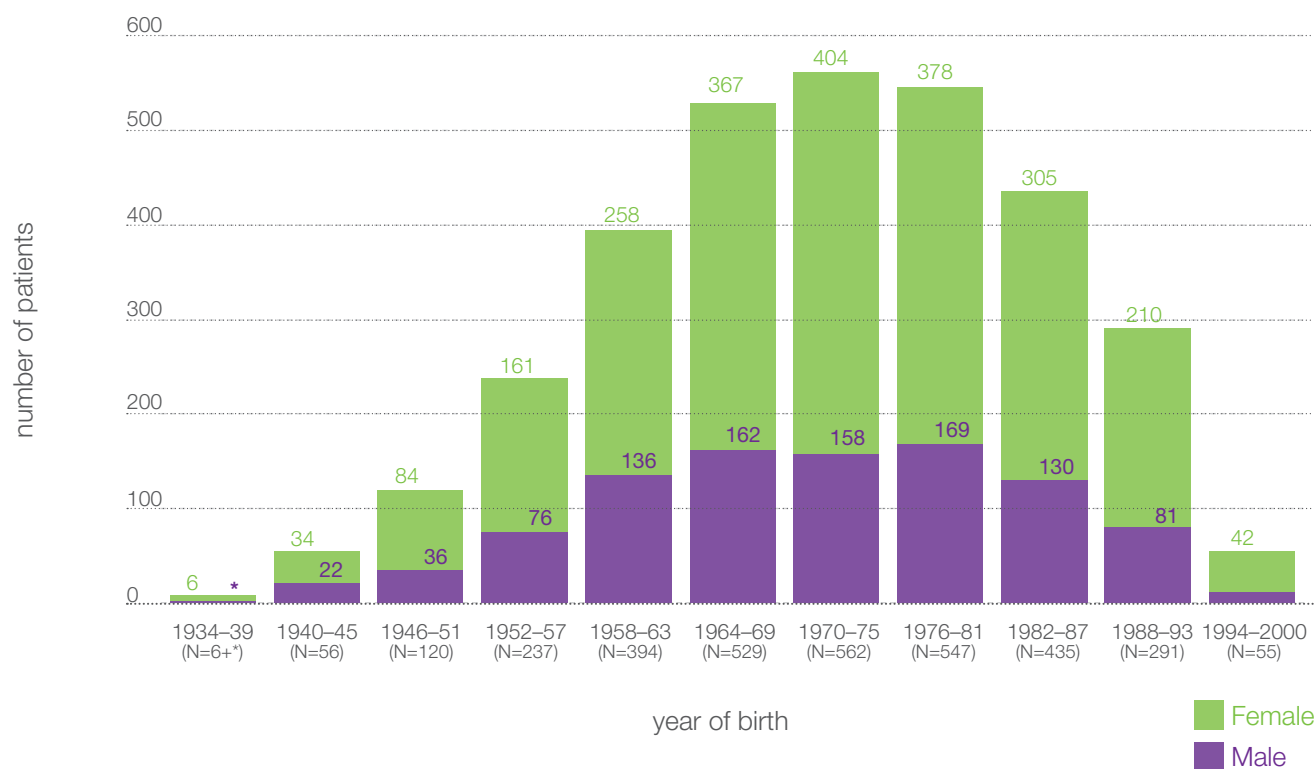
Notes:

- 1 SMSR collects data on newly diagnosed patients aged 16 years and over.
- 2 Average annual incidence within each age group was calculated using the mean mid-year gender population estimates within each 5-year age group for 2010-2016 (from the General Register Office for Scotland, estimated for the 30th of June each year) and mean incidence reported to the SMSR for each gender across this 7 year time period.
- 3 Mean age for each gender is calculated using patient date of birth quoted at time of confirmed diagnosis.
- 4 Cases for which age at diagnosis could not be calculated (N= 29: N_{males} = 10, N_{females} = 13, 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 displays the number of patients diagnosed with MS by gender and year of birth. Overall 69.5% of people diagnosed with MS are female. Interestingly men are proportionally more likely to be diagnosed with MS at an older age than women, with 39.3% of the 1940-45 birth cohort being male compared to only 23.6% of the 1994-2000 cohort. Data in this chart are incomplete as date of birth was unavailable for 13 people.

Chart 8 Percentage of people newly diagnosed with MS in Scotland, **2010–2016 data** (by gender and year of birth)



Notes:

- 1 Cases where a patient’s date of birth were not recorded (N=13; N_{males} = 3, N_{females} = 4, N_{unknown} = 6) have been excluded from the data presented in this chart.
- 2 3 males born between 1934-39 and 13 males born between 1994-2000 were newly diagnosed with MS in the period 2010-2016.
- * 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.

MS Resources and Services in each Health Board Centre.

The charts in **Figure 4** demonstrate MS specialist nursing hours, service provision and numbers of patients receiving disease modifying treatments. There have been outstanding leaps in developments of DMTs available to patients throughout Scotland. Patients have access to 12 DMTs, however this will grow in the near future. SMC approval of new drugs means more people qualify for these drugs than ever before. The number of patients receiving DMTs can account for at least one third of the MS specialist nurse caseload. The availability of these drugs brings new challenges to the MS specialist nurses in Scotland. New drugs are associated with potentially life threatening complications. The development of new DMTs has also led to impacted rates of switching between treatments and this has also increased demand in MS specialist nurse support. The aim of monitoring is to enhance patient safety and satisfaction by detecting any complications of treatment in a timely way. Patients on DMTs require monitoring on at least 4-5 occasions over the year, certain drugs require 2 weekly to 4 weekly monitoring, safety is paramount.

Despite the increase in the numbers of MS specialist nurses, the increase in workload surpasses this. There is also pressure on the MS specialist nurses to provide an equitable service to patients not on DMTs.

Each area in Scotland has different sites available to provide access for patients, this varies depending on geographical area and consists of hospital clinics, satellite clinics and home visits.

Services are exploring partnership working within their local areas looking at ways to support patients in relation to monitoring and advice while on DMTs. Health Boards require to adapt and use various resources available to ensure high levels of patient care is maintained.

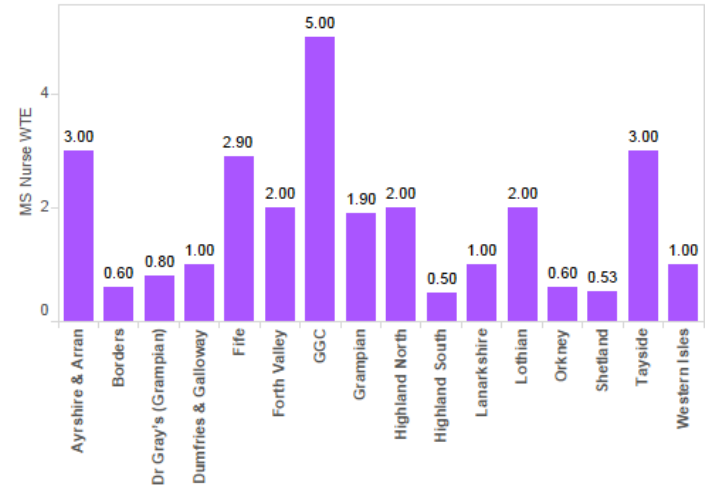
Figure 4 Overview of Health Board services, resources and MS specialist nurse total and DMT caseloads per centre

Overview

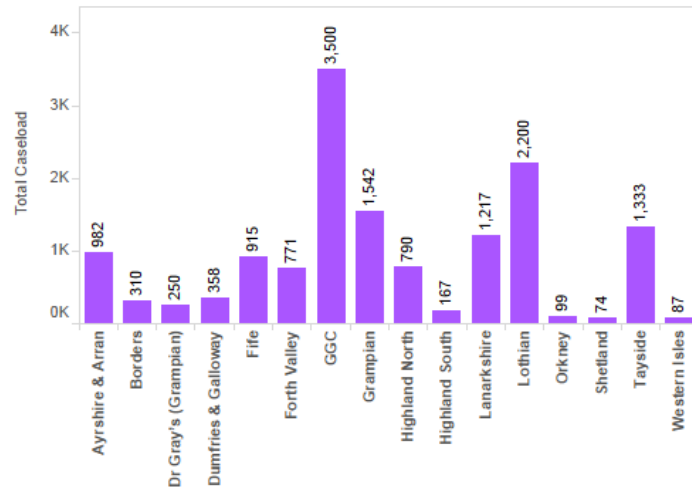
Board services

NHS Board	Hospital clinic	Satellite/Remote clinics	Home visits
Ayrshire & Arran	●	●	●
Borders	●	●	●
Dr Gray's (Grampian)	●	●	●
Dumfries & Gall.	●	●	●
Fife	●	●	●
Forth Valley	●	●	
GGC	●		
Grampian	●		
Highland North	●	●	●
Highland South	●	●	●
Lanarkshire	●	●	●
Lothian	●	●	
Orkney	●		●
Shetland	●		●
Tayside	●		●
Western Isles	●	●	●

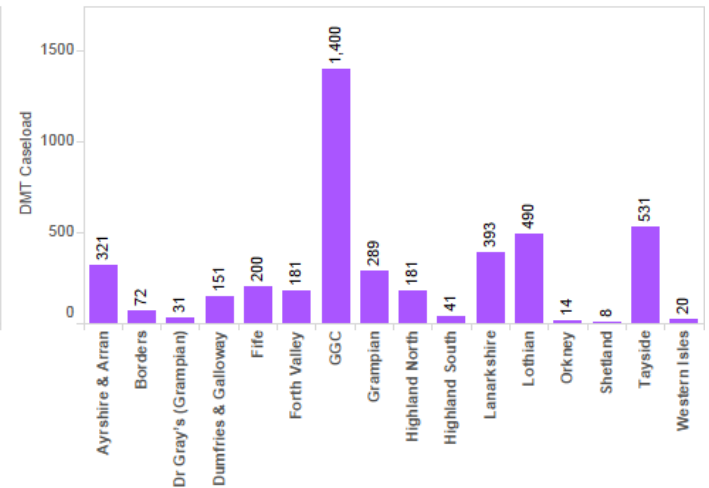
WTE by HB



Caseload by HB



DMT caseload by HB



Notes:

- 1 This information and data were provided by the MS nursing service in local Health Board centres (NHS Lanarkshire have noted a discrepancy since compiling a local database).
- 2 Quality assurance was not carried out on the data presented above.
- 3 NHS Grampian is recorded as not carrying out home visits but this relates to Aberdeen only. Moray provides both home and hospital clinic services which is represented separately for clarity.

4 Research

Linda Renfrew, Physiotherapist, NHS Ayrshire & Arran

As a physiotherapist working in the field of MS for over 20 years, any research going on in these early days was focused on developing effective disease modifying treatments for people with relapsing and remitting MS. At this time, the benefits of any break through treatments, although growing benefited few, leaving the majority of people with MS struggling to manage symptoms and disease progression. More recently with the creation of the International Progressive MS Alliance in 2012 and a revamp of the MS Society's top 10 research funding priorities, opportunities to focus on rehabilitation and symptom management research have emerged. I was first involved in MS research when undertaking a Masters degree which investigated the role of Transcutaneous Electrical Nerve Stimulation for the management of spasticity. Applying a robust research process to answer an important clinical question has subsequently driven many other research studies, all of which aim to inform physiotherapy practice and improve the quality of life of those living with MS.

Fifteen years on, Scotland now has a thriving physiotherapy research community which works together in partnership across a number of Higher Education Institutions, secondary and primary care and the voluntary sector. In NHS Ayrshire and Arran we are currently involved in 3 innovative physiotherapy research projects, all of which will positively contribute to the evidence base around effective symptomatic treatments in MS.

1. A multicentre study, has recruited 84 people with MS across 7 health boards in Scotland and is the first randomised study to compare two treatments (ankle-foot orthoses and functional electrical stimulation) for foot drop, a common symptom in MS. The results of this study are eagerly awaited and will inform clinical decisions around the prescription of these two treatments.
2. Balance Right in MS (BRiMS) is a joint venture with Plymouth University. This study has recruited 60 people with secondary progressive MS and aims to evaluate the feasibility of a novel guided self-management programme designed to reduce falls and improve mobility and balance. This programme builds on previous research where a web based physiotherapy resource was developed by Professor Lorna Paul at Glasgow Caledonian University and tested in NHS Ayrshire and Arran.
3. A third study is investigating the feasibility of undertaking high intensity interval training (HIIT) with people with progressive MS. Shona Strain, who took part in this study said "Before I took part in the study I was a non-believer in the benefits of exercise. I was surprised and encouraged by how well I managed. As time went on I noticed improvements in my sleep pattern, fatigue and leg strength. Now I am a convert and feel motivated to continue, especially as there are no drug treatments available for me at the moment".

The studies I have mentioned here are only a small snapshot of the amazing rehabilitation research which is going on across Scotland. The SMSR will play a vital role in supporting this research and ultimately improving rehabilitation treatments for people living with MS.

4.1 The SMSR Research Sub-group

The group has a representation from throughout the country with neurologists, public health consultant/ epidemiologist, member 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) 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 meets at least 3 times per year.

4.2 Current research projects utilising SMSR data

This year we have interrogated the data set and identified a number of important features regarding the MS population of Scotland.

Firstly we looked at the variance with latitude in Scotland and secondly we evaluated the impact of deprivation for the same patient group.

A Variance of MS Incidence Rate with latitude in Scotland. A study of the Scottish MS Incidence Register

McDonald JJ, Weller B, O'Neil M, Dodds H, O'Riordan JI - on behalf of the Scottish MS Register Steering Committee

Introduction: Age adjusted prevalence of MS has been shown to increase with degrees of latitude from the equator. Case data from the last 5 years (2010-15) from the Scottish MS Register (SMSR) was analysed to see if MS incidence in Scotland showed a similar trend. Individual cases were linked to small area data from the Scottish Index of Multiple Deprivation 2012 data (SIMD).

Methods: All cases from the SMSR with a diagnosis date between 2010-15 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. A regression analysis was carried out to test for statistical significance of the differences. Statistical significance was taken as $p < 0.05$.

Results: 6505 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 24 groups by latitude banding. Overall 2536 MS cases were identified, the range for the six groupings was X-Y. Population per datazone ranged from 0 – X. MS Incidence (per 100,000 per year) for the groups ranged from X to Y (mean = Z). Latitude was positively correlated with MS Incidence ($R = 0.474$, $p = 0.017$). Maps of MS Incidence were produced.

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.

B Deprivation and Geography: the associations with MS case spread in Scotland 2010-15.

McDonald JJ, Weller B, O'Neil M, Dodds H, O'Riordan JI on behalf of the Scottish MS Register Steering Committee

Introduction: Scotland has one of the highest incidence rates of Multiple Sclerosis (MS) in Europe. The relationship between MS diagnosis and social deprivation was explored. The effect of deprivation on both MS incidence and health service interaction was

studied. Geographical spread (latitude) was also studied and new MS cases in Scotland were mapped.

Methods: MS case data (2010-2015) were obtained from the Scottish MS Register (SMSR) and combined with deprivation and geographical data of the local area using the Scottish Index of Multiple Deprivation (SIMD). Patients were grouped by deprivation zone. Incidence rates were compared using χ^2 across deprivation zones. Demographics (age, sex) and patient waiting times to see an MS specialist nurse were also compared. Geographical data from SIMD was used to group MS cases by latitude bands and a linear regression analysis was undertaken.

Results: Overall, no difference was noted for MS case incidence across deprivation zones however a higher incidence of relapsing-remitting MS was seen in low deprivation areas (6.17 vs 5.49 cases/100,000 person years, $p < 0.05$). Patients from low deprivation areas presented earlier (39.79 yrs vs 41.36 yrs; $p < 0.05$). Patients from more deprived areas were more likely to wait longer than average to see an MS specialist nurse (60.1% vs 54.8%; $p < 0.05$). Latitude was positively correlated with MS Incidence ($R = 0.474$, $p = 0.017$). Maps of MS Incidence were produced.

Conclusion: This study demonstrates effects of social deprivation on MS case spread and interaction with the health service. Combined with geographical data, this may be a basis for future health care resource planning.

Future projects.

We continue to seek a solution to the problem of consent. At present the data set does not have linked data of disability, disease modifying treatments and relapse rates.

In order to do this we require consent. In Tayside Dr Kerr Grieve is undertaking a STEMS project to answer this problem. This is summarised below and the hope would be to extrapolate the technique to the MS Register.

C **A novel multiple sclerosis cohort for assessing the external validity of clinical trials of disease modifying therapy: the Scottish Treatment in Early Multiple Sclerosis (STEMS) Project**

Dr. Kerr Grieve, Dr. R. Flynn, Prof. T.M. MacDonald, Dr. I.S. Mackenzie, Dr. J. O’Riordan - on behalf of the Scottish MS Register Steering Committee

Studies which have explored the epidemiology of MS in Scotland over time have generated varied reported incidence and prevalence figures, but more confident estimates are still needed and greater understanding of how this disease affects the population is necessary. The expansion of record linkage opportunities in Scotland permits new population-based studies to take advantage of routinely collected data for improving epidemiology research with anonymised data. Disease modifying treatment (DMT) is in widespread use in this country. Previous DMT trials have been large international studies with strict entry criteria. Whilst these trials have permitted improvements in MS care, the results may not be generalizable to the Scottish MS population. Systematic assessment of the external validity of clinical trials could lead to improved healthcare provision.

We have developed The Scottish Treatment in Early MS (STEMS) Project, a new consented MS cohort, to draw together consented and anonymised data for exploring the epidemiology of MS, how it has been treated and to assess outcome at a population level. This will be piloted in Tayside and adapted before expansion to other regions of Scotland as a long-term research cohort. The study will rely on web based interaction with participants, with self-reported baseline demographics and MS disease

specific characteristics. Reliability of self-reported data will be assessed by linkage with routinely collected patient health records and assessment of medical records. To assess external validity of significant MS clinical trials, participant baseline characteristics in the cohort will be compared with the trial entry criteria. The validity of self-reported and record-linked MS outcomes will also be explored, supporting the development of pragmatic clinical trial designs for the future. The pilot phase for the STEMS Project is funded by Tenovus Scotland.

This cohort will provide a fuller understanding of MS epidemiology and management in Scotland in the longer term. Critically, early data will form the basis of an assessment of the validity of significant DMT clinical trials, supporting the improvement of future study design.

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

NHS Fife

The NHS Fife MS Nursing Service are committed to improving the journey for patients who receive a diagnosis of MS in Fife. In doing so, this will meet Standard 15.2 “Contact with an MS Clinical Nurse Specialist is offered at diagnosis. Contact is made within 10 working days”.

The MS specialist nurses at NHS Fife Rehabilitation Service are responsible for completing the MS register dataset and have also been improving systems to ensure that every register form is completed accurately and provides a true representation of MS incidence and prevalence rate for NHS Fife.

We are aware that the reason standard 15.2 in NHS Fife is not met is due to a delay from date of diagnosis to the MS nurse receiving the referral. Once a referral is received, the MS specialist nurse can make contact with the patient within the required timeframe.

A 6 month email referral system was proposed in March 2016 to assess if this improved the timeline for patients.

Results

There were 22 new diagnosis of MS during this period.

10 patients were referred via email. 9 of these emails were sent on the day diagnosis was confirmed. 9 out of 10 met the standard.

The other 12 referrals were via clinic letter, only 2 of which were received within 8 days of diagnosis.

Only 50% of referrals met standard 15.2 (9 via email & 2 via referral letter). Medinet – the previous Neurology waiting list initiative, caused excessive delays due to not referring directly to the MS specialist nurse at the same time as referring to NHS Fife Neurology Service.

Recommendation

An email referral system is the most efficient way to improve the timeline for patients and meet the standard. This referral method should be used instead of a referral letter.

When a referral letter for a newly diagnosed patient has been dictated by neurology secretaries, they now prioritise it as urgent; and reminders will be sent to the Neurologist if the email referral system is not being utilised.

Other improvements

We now have admin support to check all incidence forms for completeness prior to sending onto ISD. This has resulted in a reduction in the workload required to complete missing data at the end of every year.

We have a newly diagnosed log which details the date of when the register form has been completed and sent. This ensures validity of incidence of new diagnoses in NHS Fife and can be quickly cross referenced at end of year for accuracy.

The Neurology Waiting List Initiative have been contacted to advise on ability to refer direct to the MS specialist nursing team once a confirmed diagnosis has been discussed with the patient rather than only referring onto Neurologist in NHS Fife.

NHS Lothian: Telephone Review Clinic

Dimethyl fumarate (DMF) was added to the NHS Lothian formulary in August 2014 and became our most frequently used disease modifying treatment (DMT). This resulted in an increased number of patients on DMTs requiring regular monitoring. A comparison between numbers on treatment in March 2013 with December 2014, showed a 30% increase in use of all DMTs (although this was largely driven by increased DMF use). A comparison of the number of patients seen in the MS specialist nurse clinics demonstrated a 30% increase in the number of nurse appointments over a 1 year period.

In order to accommodate this increase, patients were being overbooked into inappropriate clinic slots (new patient and urgent return) and the clinic times were also extended by starting the clinic earlier and finishing later. As a result of the increase of patients requiring monitoring appointments the ability of the MS clinic to respond to relapses and new patients was being negatively impacted. Both of these services are essential for our MS team to comply with current quality standards.

We discussed this as a team and it was agreed that some of the review appointments could be done over the phone. The consensus was however that a six monthly review in person was still important. A system was established whereby if patients required 3 monthly bloods but were otherwise stable, they could be reviewed by telephone. They were asked to have routine bloods checked locally (by their General Practice, if they were agreeable) in advance of the telephone consultation.

We performed an audit of activity taking our patients' views into account. Each clinician was asked to complete an 8 question survey to determine whether the patient was suitable for a telephone review. Over a 2 week period (23rd March to 3rd April 2015) 16 patients came in for DMF review. Seven patients were deemed not suitable. The reasons included were: patients experiencing troublesome side effects, patients experiencing a relapse, concerns about adherence to treatment and patient preference to be seen in clinic. Therefore 9 extra patient clinic slots would have been available over a 2 week period if a telephone review was in place.

Since starting the clinic in 2015 this system has proved popular with a growing number of patients and provides a useful way of monitoring patients who are stable on treatment. It gave patients choice and hopefully aids adherence to treatment. In the first 6 months of 2017 we have averaged 32.3 patients seen in a virtual clinic each month. We have now extended the virtual clinics to include patients on other DMTs which require regular monitoring.

6 Patient Reference Group

When I was initially asked to contribute a short piece of writing from the SMSR Patient Reference Group perspective that would be included in the National Report, I was somewhat hesitant, as I have only been to one Patient Reference Group meeting, and one National Conference – would I have enough to say, and would there be anything of relevance or interest? The more I thought about it though, the more I realised I really did have something to say with what I feel is of relevance, and hopefully of interest, and in fact I had pretty much said it recently to 2nd year nursing students at Dundee University as a patient invited to have a chat and be interviewed about being diagnosed and living with a long term, potentially chronic, condition.

When I was asked about my response to when I was initially diagnosed with MS in September 2013, the main point that seemed to stick in my memory was about being put on a disease modifying drug, and not having much, if any, say in the matter. I fully appreciate that medication must be considered – but it is part of a much bigger picture, as when it comes to person centred care, what should always be remembered is the person – not the condition. We all have an identity, a history, a background – family, friends, colleagues, work, hobbies and dreams – MS is just a part of that. So why is it only the condition that is being treated, and not the whole person?

What I would like to see in the very near future when people are diagnosed with MS, is availability of an information pack covering the wide variety of information, advice and support available – both within the NHS, the third sector, and other sources. Although many people may not feel they are initially in the right frame of mind to look at such an information pack, it is something they could eventually pick up and read through – maybe the next day, weeks or even months after diagnosis. Quite simply, when they themselves were ready.

Such a pack would contain information on psychological support, physiotherapy, exercise, diet/nutrition, mindfulness/meditation, support groups, occupational therapy, financial support/benefits, employment, relationships, alternative and complimentary therapies, and full information on the choices of the disease modifying drugs available. All of this information is crucial in order to enable true person centred care, not least when it comes to the decision on whether or not to use a disease modifying drug, and which drug may be chosen.

Obviously setting up and creating such an information pack would initially be expensive – gathering together all the relevant facts, information and advice would take time and resources, but once this was all pulled together and in place, long term it would be highly likely to help reduce costs within the NHS, as people would have all the information necessary to help them make informed choices, feel more able to communicate with their health care professional, and ultimately take some responsibility for their own healthcare – a holistic approach which creates a positive feeling of wellbeing and empowerment.

Quite simply it would be a win-win situation for both the person and the NHS – as both would benefit from this relatively simple resource.

Sometimes it really is the simplest of things that can make a big difference, and have a truly positive impact.

7 National Advisory Committee for Neurological Conditions (NACNC) MS Sub-group

The National Advisory Committee for Neurological Conditions (NACNC) was set up by Scottish Government to:

- Provide advice to the Scottish Government on neurological conditions to support the development of national policy;
- Be widely recognised as having the ability to lead, collate and represent the views of the neurological community, including health care professionals, third sector organisations and service users;
- Create and offer opportunities for networking and communication for all neurological stakeholders and
- Improve patient outcomes for those with neurological conditions by working to embed improvement in Health Boards, Integrated Joint Boards and Local Authorities for safe and effective treatment and care.

As the scope of work is challenging, and as the neurology community is large and diverse, three condition sub-groups were set up to support the main committee. One of these is the MS sub-group. It is co-chaired by Dr Jonathan O’Riordan, Consultant Neurologist, NHS Tayside, and Mags MacKenzie, External Relations Officer (Scotland – West) , MS Society Scotland. The group membership includes people living with MS, clinicians, nurses, allied health professionals, and representatives of third sector organisations.

The main national advisory committee for neurological conditions identified a number of high priority tasks for 2016-2018. The MS sub-group has reviewed these and is developing a workplan to look at:

- Incidence / prevalence data;
- Diagnostic phase - use of multi-disciplinary diagnostic clinics to improve diagnostic pathway, provide well-rounded service supporting early treatment, advice and education, self-management;
- Early relapse remitting multiple Sclerosis (RRMS);
- Progressive MS;
- DMTs and prescribing patterns, and recording decisions to prescribe;
- Symptomatic treatment, including access to Botox and Functional Electrical Stimulation (FES);
- Neuro rehabilitation and
- Manpower- use of clinical specialists, and exploring models of care to support people with MS better.

Work has commenced with NHS Information Services Division to explore prevalence rates of MS in Scotland, These discussions are at an early stage, are being done in partnership with representatives of the SMSR, some of whom sit on both groups.

The NACNC will be distributing a workforce questionnaire to gather information on the workforce in neurological services across Scotland. This questionnaire will gather information on the grade and job titles of specialist nurses and AHPs.

If you have any questions about the work of the NACNC MS-sub-group, please contact Mags Mackenzie by e-mail: Mags.Mackenzie@mssociety.org.uk or Kirsty Forsyth by e-mail: Kirsty.Forsyth@gov.scot.

8 Progress

8.1 Collection of data

Forms continue to be completed by the MS specialist nurses in Health Boards and all Health Boards scan forms and email them to the central team. This improves efficiency and security of transmission of data. Currently an electronic form is being developed and this will pilot in one Health Board next year. This would further streamline and improve the accuracy and efficiency of data collection.

8.2 Dataset and definitions

A review of the SMSR dataset and definitions was undertaken in 2016 and refined with new incidence forms now adopted in all Health Boards.

8.3 Routine reporting

Distribution of quarterly reports to MS specialist nurses and Clinical Leads reflecting activity for the previous quarter and performance against national Neurological Standard 15.2 (2009) continues. The quarterly reports are reviewed by the clinical co-ordinator and MS specialist nurse to explore and investigate exception reporting and provide the opportunity for service improvement locally.

8.4 SMSR National Meeting

Due to the success of the first SMSR National Meeting held October 2016 it has been proposed to hold a further meeting in 2018.

8.5 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. In 2016 it was agreed that incidence forms would be checked for incomplete data by peer review, admin or centrally before reaching the analyst. This improves efficiency and accuracy of data collection and analysis.

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

Case note validation planning was undertaken in 2016 with the first visit arranged with NHS Greater Glasgow & Clyde in 2017. This will be presented in next year's report.

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Appendix B Feedback from Chief Executives

NHS Ayrshire & Arran

NHS Ayrshire & Arran has an estimated population of 370,560 and approximately 1,020 people with a diagnosis of MS being managed by the MS Team at the Douglas Grant Rehabilitation Centre in Irvine. In 2016, 41 new patients were diagnosed with MS, which is a slight increase on previous years. One third approximately of the active caseload are on a disease modifying treatment. The MS service is fully multidisciplinary and includes MS specialist nurses, AHP and other services. The MS Service is integral to the Neurological Rehabilitation Service and a non-medical clinical lead for neurological rehabilitation supports service development. The MS service is supported by the Neurological Rehabilitation Managed Clinical Network and a Neurological Services Improvement Group within NHS Ayrshire and Arran.

The NHS Ayrshire & Arran MS service has a neurologist 4 sessions each week. This is a split post with the Queen Elizabeth University Hospital, NHS Greater Glasgow & Clyde. There are eight MS specific clinics held at the Douglas Grant Rehabilitation Centre and/or at peripheral clinics in community hospitals at Girvan and Cumnock. These clinics are primarily MS specialist nurse and AHP led. The team is looking to establish bi-annual MS clinics on the Isle of Arran.

All the MS specific national standards continue to be met other than “MS nurse contact being made within 10 working days” (Standard 15.2). There has been a 20% improvement on the previous 12 months. There are now two full-time MS specialist nurses and one MS support nurse in post. As a result of the increase in the availability of disease modifying treatment, the MS support nurse has been a crucial development in affording the MS specialist nurse to concentrate on providing specialist advice in the management of the disease.

The Douglas Grant Rehabilitation Centre offers a single point of contact, and patients are encouraged to self-refer at any time should the need arise. Patients with a suspected MS relapse are offered a clinic appointment within 5 working days at our MS nurse assessment clinic. Routine MS review is offered by a member of the Multi-Disciplinary Team (MDT). Two members of our MS MDT are non-medical prescribers and can support with symptom management.

Patients who are diagnosed with Clinically Isolated Syndrome (CIS) have full access to the MS MDT service and are kept under routine review.

Newly diagnosed patients are invited to a ‘Getting to Grips with MS’ educational event. There are also regular education events for those affected by MS at various locations throughout Ayrshire over the year, run in partnership with the MS Society Ayrshire & Arran Group, and sit alongside well established peer support groups.

We organise study days annually for staff, including health and social care support workers from secondary, primary and community care settings.

NHS Borders

In 2016 NHS Borders recorded the lowest rate in Scotland in respect of the incidence of MS per 100,000 of the population and has not experienced any increase in the annual number of newly diagnosed cases since 2010 (7 new cases each year from 2011 to 2015, 6 new cases in 2016). The latitudinal gradient in MS prevalence is acknowledged as being in all likelihood significant.

All newly diagnosed MS patients within NHS Borders receive their diagnosis at the MS clinic. Immediately following the clinic, patients are discussed by a consultant and MS specialist nurse and the MS specialist nurse will then arrange to contact the patient. However formal referral is via clinic letter which average 18 days. Therefore whilst NHS Borders performs below the national average in respect of Neurological Standard 15.2, in practice referral takes place on day of diagnosis. All

patients in 2015 were contacted by the MS Nurse within 20 days. In 2015 it was one of only three Boards within which 100% of patients had contact from an MS specialist nurse within 10 working days of receipt of referral. In 2016, five of the six new patients diagnosed had contact from the MS specialist nurse within 10 working days last year.

The neurological service in NHS Borders is delivered by 2 full time consultant neurologists and specifically with regard to MS has 0.6 wte of an MS specialist nurse.

The MS service provides specialist nurse led clinics at Borders General Hospital (BGH) on alternate weeks, with three monthly peripheral clinics at Peebles and Eyemouth. The MS specialist nurse also carries out home visits for patients throughout the region. Patients are provided with contact details and encouraged to self-refer to the MS specialist service. Consultant led MS clinics take place at BGH on alternate weeks. A three monthly spasticity management/botulinum clinic is run jointly by the neurologist, a neurophysiotherapist and an orthotist. Both the neurologist and MS specialist nurse are available for telephone and email advice for patients and GPs throughout the week. Weekly regional neuroinflammatory meetings are held at the Anne Rowling Clinic Royal Infirmary of Edinburgh for review of complex cases, with local participation by videoconference link.

Patient feedback relating to MS service is collected and considered in relation to how routine services are delivered.

NHS Borders is in the short run looking to improve the administrative support available to the MS specialist nurse and in the longer term is considering other service development opportunities within the context of its' future clinical service strategy".

NHS Dumfries & Galloway

Nil response received.

NHS Fife

The MS nursing service are committed to improving the journey for patients who receive a diagnosis of MS in Fife. The MS specialist nurses at Fife Rehabilitation Service (FRS) are responsible for completing the MS register dataset and have been improving systems to ensure that every registration form is completed accurately.

15.2: The main issue meeting this standard is the time taken for the referral to be received. A local audit was carried out and highlighted that an email referral was more effective for enabling patients to be seen by the MS specialist nurse within 10 working days of diagnosis. We continue to implement this locally and the advice to consultant neurologists locally is now to refer electronically where possible.

14.1a & 14.1b: Patients have access to an MS team working within both acute and community teams. The acute team have a lead consultant who specialises in diagnosis and management of MS supported by a disease modifying treatment (DMT) specialist nurse. The FRS in the community provides specialist assessment and rehabilitation for all stages of MS and other neurological conditions on an outpatient and community basis. Both teams work together when addressing needs of people with MS.

14.2a: The MS specialist nurses at FRS provide a newly diagnosed course called "getting to grips with MS". This is run twice per year and is offered to all those diagnosed within the first year of diagnosis.

14.2b: Family members are also invited to attend the above course. No other structured programme is offered. Individualised training is carried out by the team relevant to patients' needs.

14.3: Currently there is no structured programme in place. Training is provided to healthcare professionals as required. The FRS are currently assessing the benefit of a new online MS training programme.

15.1/15.2: Patients referred with symptoms suggestive of central nervous system demyelination are currently offered investigation, and if undertaken, the results are explained and therapeutic options discussed with them.

15.3: Patients diagnosed with Clinically Isolated Syndrome of demyelination remain under the care of their neurology consultant unless the diagnosis changes to MS.

16.1a: Currently not all NHS Fife patients are routinely reviewed on an annual basis due to number of reviews required. Work is underway to assess the effectiveness of an annual review including whether face to face or telephone review is preferred by patients.

16.1b: The option to self-refer is the main route for all patients. Once referred, patients have ongoing access without need to go via GP.

16.2a & 16.2b: MS specialist nurses at FRS produced a Relapse Management Toolkit which provides information on services available to patients who relapse. If a patient contacts the MS specialist nurse line with a suspected relapse the call must be returned within 48 hours and the appropriate assessment completed (local standard). MS specialist nurses have direct access to the multidisciplinary team if required for management of disabling relapses. Any relapse activity is reported back to the DMT service.

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

NHS Forth Valley

The number of people with MS in NGS Forth Valley is 770. The number of patients on DMTs is 195. A small number of newly diagnosed patients failed to meet standard 15.2 of 10 day contact from an MS specialist nurse. These referrals took longer to reach the service for a number of reasons. This has been remedied by consultants contacting the MS specialist nurse on the day of diagnosis or as soon as possible thereafter.

The MS Service has two full time MS specialist nurses and one specialist consultant; several initiatives have been put in place to cope with the increasing number of patients and the complexity resulting from DMTs.

The Neurology Department is now “paper light”. An electronic database is in place containing information on all patients with an MS diagnosis in Forth Valley. An electronic communication document is used to provide clinical advice to GPs, thus ensuring no delay in patients receiving medication or GPs being unaware of newly prescribed medication. Referrals to other services in Health and Social services are made electronically.

With the growing use of biologics in relapsing remitting multiple sclerosis an alert has been put in place on the clinical portal to ensure Doctors are aware of these treatments if patients are admitted out of hours.

14.2a - Newly diagnosed patients are offered a one hour appointment with the MS nurse, are provided with information individually structured for them, contact details for the telephone advice line and an appointment with the Specialist Nurses Consultant. Patient newly diagnosed groups are supported by a specific group seminar. The Carers Centre Care provides community based accommodation for group work.

14.2b - Patients and families can contact the telephone advice line throughout the course of the condition, patients and family are invited to attend the newly diagnosed group. A directory of locally available resources within the third sector is under development. Contact details are included in the revised MS Service information leaflets which are in development.

14.3 - Training is provided to the Independent Sector. A structured education programme for staff in NHS Forth Valley Royal Hospital is under development.

15.1, 15.2 - General neurology.

15.3 - A Leaflet is provided at General Neurology clinics. Patients are referred to MS specialist nurses.

16.1a: Telephone clinics have been established to ensure attendance at outpatients is only used where appropriate. Tele-medicine options are currently being considered to support patients.

(16.1b): (16.2a) (16.2b) - A telephone advice line operates. In addition to this recently a daily rapid access telephone clinic is in place on the electronic appointment system. Patients are triaged on the phone initially and reviewed in outpatients within 24 hours for relapse assessment. Medication is arranged where required and a referral made to appropriate services, i.e. physiotherapy, social work.

16.3 - The service manages all DMT prescriptions, liaising with finance, pharmacy and homecare. All eligible patients are offered DMTs.

NHS Grampian

Nil response received.

NHS Greater Glasgow & Clyde

Nil response received.

NHS Highland

In NHS Argyll & Bute an issue was identified whereby some patients receiving their diagnosis from neurologists based in Glasgow were initially referred incorrectly to NHS Greater Glasgow & Clyde MS specialists. The resultant delay in redirecting the referral created challenges to meet the timescales set out within standard 15.2. As the Argyll and Bute MS nurse service has become more established and following awareness raising activities improvements are now being seen.

A potential ongoing challenge for meeting the ten working days standard occurs when the single handed MS specialist nurse is on leave. Planned improvement work going forward includes systematically contacting the team of MS specialist nurses and neurology secretaries to inform them of any absence of more than a week, to enable another MS specialist nurse in Glasgow to contact newly diagnosed patients within ten working days.

In the Highland Health and Social Care Partnership the standard can become challenging in situations when receipt of the referral following diagnosis has been delayed. A system has been implemented to prioritise first contact for newly diagnosed patients. The MS specialist nurses have co-ordinated their work patterns to ensure one of them is available across the working week to support this priority, whilst meeting their commitments to peripheral clinics, home visits and training schedules throughout the partnership geography. This should deliver further improvement to compliance with the standard.

NHS Lanarkshire

A number of the figures are not in keeping with our database, which we have reviewed over the last 2 months. Please note the following data have been amended in the report;

- The database records show we have 1217 individuals with a diagnosis of MS in NHS Lanarkshire, not 1500 as referred to in the report.
- 393 of these individuals are on DMT therapy, not 500 as referred to in the report.

For information, a further 295 individuals received active support over 2015/16 by our MS specialist nurse, who are not on a DMT.

There are, as with other Health Boards a number of individuals with prevalence of MS (approximately 283), however these are not actively seen by MS services and are managed through local GP services.

We can confirm we continue to offer hospital clinic appointments, satellite/remote clinics and home visits.

With regards to developments and improvements in our service delivery, I can advise we previously had 1 WTE MS specialist nurse. The current situation is that our MS specialist nurse has left the organisation and we are currently recruiting to 2 WTE MS specialist nurses, thus an additional 1 WTE post. There are interim measures in place with 2 very experienced MS specialist nurses, working with the MS specialist nurses in NHS Greater Glasgow & Clyde and our local MS consultant to provide cover.

We are working in partnership with the MS Trust and have a full training package for our new recruits to work through once appointed to, in keeping with the standards required as related to in your letter.

We can confirm that interim measures are in place to ensure that 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 of the diagnosis.*) is met, as described above, we are working in partnership with NHS Greater Glasgow & Clyde who are providing an MS specialist nurse to see all newly diagnosed patients. They are also providing support and mentoring to the specialists who are providing interim cover until our recruitment process is complete.

With regards to the other Neurological Standards referred to in your letter, NHS Lanarkshire continues to offer a multidisciplinary approach to MS treatment, with a local consultant who specialises in the diagnosis and management of MS, who works alongside our nursing staff and patients and carers to deliver the service. Additional input is provided by suitably trained disciplines when appropriate.

NHS Lanarkshire is committed to continuing to improve our services to people with a diagnosis of MS with the additional MS specialist nurse and plans to improve local knowledge and skills of our community teams through continuous professional development.

NHS Lothian

Nil response received.

NHS Orkney

Nil response received.

NHS Shetland

NHS Shetland is committed to providing expert person centred care to patients with neurological conditions and other long term conditions in the primary, secondary and social care setting. The MS specialist nurse acts as a co-ordinator of care and navigator for MS patients throughout their care pathway, with strong clinical links established with NHS Grampian (consultant neurologists), to ensure expert medical management is delivered to MS patients living across NHS Shetland.

The post of the MS specialist nurse is based within the secondary care setting with governance provided by the consultant neurologist (NHS Grampian). The MS specialist nurse is a highly skilled practitioner who possesses advanced nursing skills such as independent nurse prescribing, advanced neurological assessment skills, and holds a post basic module in MS / Neurology with considerable experience in chronic disease management. This enables NHS Shetland to continue to provide individualised and timely care for MS patients, living in a remote and rural setting requiring symptom assessment and management particularly at times of relapse, in close conjunction with the local multidisciplinary team.

The MS specialist nurse for NHS Shetland is an autonomous practitioner who provides a nurse led service for MS patients their carers and relatives from diagnosis onwards through to end of life care. The MS specialist nurse provides expert nursing advice and education to patients and their carers on all aspects of multiple sclerosis management, including investigations, diagnosis and available treatment throughout the course of their illness. Their education programme is individual and tailored according to the patients and carers needs.

During 2017-2018 the MS specialist nurse will be working closely with the multidisciplinary team to;

- Devise individual anticipatory care plans for all MS patients in collaboration with the patients and their carers.
- Will lead in the local delivery of disease modifying drug therapies as part of shared care protocols with NHS Grampian, including collecting data for audit.
- Provide pain and symptom management and relapse assessments to MS patients, in conjunction with the neurology team (NHS Grampian).
- Continue to support and develop the telemedicine clinics with the consultant neurologist (saving patients and carers travelling to Aberdeen for appointments 200 miles away).
- Develop a collaborative working relationship with the Shetland Macmillan team with regard to management of Long term conditions .The Macmillan oncology nurse will attend the telemedicine clinics to maintain neurological assessment skills and provide some sustainability for the telemedicine neurology clinics (additional support to this service).
- Provide education and training to support the wider multidisciplinary team and care home staff involved in caring for MS patients.
- Provide education and information to newly diagnosed patients and their families
- Continue to collect and collate data for the Scottish Multiple Sclerosis Register and in this way will contribute to national, regional and local work regarding service evaluation and quality improvement.

NHS Tayside

Nil response received.

NHS Western Isles

The Neurological Managed Clinical Network (NMCN) take responsibility for service developments for Neurology Services, with regular reports directly to the Board on progress. The implementation of the Neurological Strategy is being led by Public Health Planning and Development team, supported by the specialist nurses.

There are effective working links for neurological services between NHS Western Isles and NHS Greater Glasgow & Clyde in place. Patients are also referred when necessary to NHS Highland for specialist rehabilitation and on occasion to private sector providers when NHS resource is not available. GPs and hospital physicians may contact the Institute of Neurological Sciences, Glasgow on call service for neurology, 24 hours a day, 7 days a week for discussion of urgent cases.

We have a MDT for all neurological conditions including MS constituting of local rehabilitation services (Speech and Language Therapy, Occupational Therapy, Physiotherapy), social work, carers, nursing homes, NHS Greater Glasgow & Clyde consultant and rehabilitation units. This is done through the utilisation of pathway to MS specialist nurse on diagnosis (for established and new diagnosis)

For MS patients we currently offer weekly outpatients clinic; GP satellite clinics; VC from patients' home to consultant; patients Jabber in from Southern Isles.

The Neurology Services Strategy is currently being updated. Over the next 12 months a priority for the Neurology Managed Clinical Network (NMCN) will be to re-examine clinical pathways, guidance for GPs, and with recent training developments of the MS specialist nurse will be looking to develop and strengthen which specialist services can be offered locally, reducing the need for patients to travel to mainland centres. This will integrate the service and increase the level of collaboration planning and development between the two boards.

Recent Improvements/Initiatives

1. Tysabri service is now offered island wide – with staff targeted in training in this service to increase service awareness and capacity;
2. A bladder scanner has been purchased to allow patients to be scanned in their own homes and to allow initiation of appropriate treatment liaising with continence advisor and Urologist;
3. MS Nurse Pro delivered – 40+ professionals across all sectors undertook training and are able to act as point of contact for any patient to ensure patient journey is quick and efficient;
4. Jabber video conferencing links to rehab consultants on mainland now offered;
5. We are in the process of installing the Florence system for neurological patients for relapse monitoring/blood monitoring;
6. We are looking to run a pilot project with the “Attend Anywhere” telecare software with MS patients due to start late Autumn time;
7. MS specialist nurse has achieved her prescribing and neuro-examination awards which will allow more localised services to be offered, allowing care closer to home;
8. Given the current redesign of MS services in NHS Greater Glasgow and Clyde, we have an optimum opportunity to feed in to this and streamline our systems to ensure a smooth pathway.

Appendix C Organisational structure of SMSR

The SMSR is a national register within the Scottish Healthcare Audits (SHA) of the Public Health Intelligence (PHI) (formerly Information Services Division) of NHS National Services Scotland (NSS). The register has its own steering group of key stakeholders who provide strategic direction and clinical input to the register team optimising the use of the data. See the SMSR website (www.msrs.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 / Iain McDermid | Information Analyst

Martin O'Neill | Principal Analyst

Gillian Gillespie | Data Support Officer

Derek Murphy (Information Analyst) left the SMSR during 2016 to take up a new and exciting research position at Cambridge University. The SMSR team would like to take this opportunity to thank Derek for his contribution and wish him well in his new venture.

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. MS specialist nurses and others employed in each Health Board collect the data for the Register. Staffing levels vary widely between hospitals as can be seen in Figure 4. 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.

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 Trust—What is MS?

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

Future MS

<http://future-ms.org/>

Acknowledgements

The Steering Group of the SMSR would like to thank the staff in all of the neurological and neurological rehabilitation units in Scotland for their help with data collecting and checking. The clinical leads for each of the hospitals are listed in the table below:

NHS Board	Hospital / Health Centre	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 Victoria Hospital	Lance Sloan Uwe Spelmeyer
Forth Valley	Forth Valley Royal Hospital	Christian Neumann
Grampian	Aberdeen Royal Infirmary	Margaret-Ann MacLeod
Greater Glasgow & Clyde	Institute of Neurological Science, Queen Elizabeth University Hospital	James Overell Stuart Webb
Highland	Raigmore Hospital	Chavier Artal
Lanarkshire		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 specialist nurse.
- ** Diagnosis made by a General Neurologist from Institute of Neurological Science, Glasgow.

The MS specialist nurses who co-ordinate the work of the SMSR locally for each of the hospitals/clinics are listed in the table below:

NHS Board	Hospital / Health Centre	Register Co-ordinator
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Jacqueline Downs
Borders	Borders General Hospital	Lorna Rogerson
Dumfries & Galloway	Dumfries & Galloway Royal Infirmary	Joy Millar
Fife	Cameron Hospital	Debbie McCallion
Forth Valley	Forth Valley Royal Hospital	Madeleine Steele
Grampian	Aberdeen Royal Infirmary Dr Gray's Hospital, Elgin	Mairi Maguire Gillian Alexander
Greater Glasgow & Clyde	Institute of Neurological Science, Queen Elizabeth University Hospital	Lynn Cherry
Highland	Raigmore Hospital Lorn & Islands Hospital	Lindsay Parks Cheryl Howe
Lanarkshire	Greenhill Health Centre, East Kilbride	Vacancy
Lothian	Royal Infirmary of Edinburgh	Matthew Justin
Orkney	Balfour Hospital	Moira Flett
Shetland	Gilbert Bain Hospital	Elizabeth Clarke
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;
- Health 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 publications team as part of the ISD of NHSScotland 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 for his 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 Dr Niall MacDougall, Dr James Overell, Dr Elizabeth Visser, Frances Benison, Linda Renfrew, Derek Murphy, Martin O'Neill, Iain McDermid, Dr Jonathan O'Riordan, Debbie McCallion, Matt Justin, Chrissie Watters and Dr Belinda Weller with contributions from Health Boards.

Scottish MS Register Contact List

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

Scottish MS Register

e-mail: NSS.ISDscottishmsregister@nhs.net
tel: 0313 314 1209

Chrissie Watters | National Clinical Co-ordinator

e-mail: cwatters1@nhs.net
tel: 0131 275 6111

Iain McDermid | Information Analyst

e-mail: iain.mcdermid@nhs.net
tel: 0131 275 7419

Martin O'Neill | Principal Information Analyst

e-mail: martin.o'neill@nhs.net
tel: 0131 275 6244

Gillian Gillespie | Data Support Officer

e-mail: gilliangillespie@nhs.net
tel: 0131 275 7419

Hazel Dodds | Senior Nurse

e-mail: hazeldodds@nhs.net
tel: 0131 275 7184

Stuart Baird | Service Manager

e-mail: sbaird@nhs.net
tel: 0131 275 6043

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

e-mail: belinda.weller@luht.scot.nhs.uk
tel: 0131 537 2403

