

Scottish Multiple Sclerosis Register

National Report

10th September
2019

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Foreword

The Scottish Multiple Sclerosis Register (SMSR), now in its ninth year, is a unique database of confirmed diagnoses of patients with MS. In 2018, 536 new patients with a confirmed diagnosis of MS were added, bringing the total number of patients newly diagnosed and reported over the nine-year period to 4,256.

I welcome this year's SMSR report, which sets out the achievements and progress made during 2018. This includes a further increase both in the percentage of newly diagnosed patients contacted within 10 days of diagnosis in 2018 from 73.1% to 81.2% and those contacted by a MS specialist nurse from 96.4% to 98.1%, demonstrating a rising trend in performance over the past few years.

In this foreword last year I spoke about Realistic Medicine and our vision for the future of healthcare in Scotland. I highlighted that together with the utilisation of technologies, digital innovations and adaption of our cultural approaches, the SMSR is enabling targeted research studies to continually advance improvements in the delivery of services that support people to make informed choices about their care. My annual report this year, entitled Personalising Realistic Medicine, recognised that enthusiasm around the personalised approach has continued to build and has become a central theme in people's minds when they think about delivering Realistic Medicine. The SMSR plays an important role in helping us understand the epidemiology and incidence of MS across Scotland, which in turn is helping service providers to focus on improving equity of access to services for everyone diagnosed with MS regardless of where they live in Scotland.

We are committed to improving and continually driving forward improvements for people living with Neurological Conditions, like MS, to ensure the people of Scotland receive the best possible care and support that they require. Over the past 18 months the Scottish Government has worked with people with lived experience, third sector organisations and healthcare professionals to develop Scotland's first National Action Plan for Neurological Conditions setting out our vision for ensuring people can access the care and support they need to live their life well on their own terms. We look forward to working closely with people with lived experience, third sector organisations and healthcare professionals on the implementation of the national action plan over the next five years.

On behalf of the Scottish Government, I would like to offer my thanks and appreciation to the analysts and specialist clinical teams across Scotland – whose dedication and commitment make SMSR such a valuable tool in enhancing our epidemiological understanding of MS and supporting improvements throughout the country for those living with MS.

Catherine Calderwood

Chief Medical Officer

Welcome

It is a great pleasure to introduce the ninth annual report of the Scottish Multiple Sclerosis Register (SMSR). The SMSR is a national Register within the Scottish Healthcare Audits programme within NHS National Services Scotland (NSS). The register has been prospectively recording new diagnoses of MS since 2010.

Multiple sclerosis is an important and relatively common disease in Scotland and the register is improving our understanding of the epidemiology of the disease in our country. Our ultimate aim is to improve healthcare for people living with MS in Scotland. Over the past year more research using the register has been performed which may help us understand even more about the disease. The accurate numbers that we can give the Scottish Government and the NHS should allow better service planning for those affected by MS.

The data on which this report is produced are provided by Neurologists and MS clinical teams via a standard electronic proforma which incorporates the patient journey from referral to diagnosis, including referral to a MS specialist nurse.

Data have now been collected on 4256 people with a verified diagnosis of MS, 536 of whom received a diagnosis in 2018. The register relies on the ongoing support of MS specialist nurses, neurologists and rehabilitation consultants, Allied Health Professionals (AHPs) and managers who submit data on people with a confirmed diagnosis of MS using a standard on-line proforma. The data are securely stored within NSS and are analysed to explore epidemiological trends in MS and also to audit availability and access to MS services throughout Scotland.

This report is the result of a lot of work by a lot of people. The analytical staff at NSS process data to produce the report but they rely on the hard work of MS specialist nurses throughout Scotland who collect the information and submit it to the register. The steering group for the register consists of MS neurologists, MS specialist nurses, AHPs and patient representatives, along with representatives from the MS Society and the MS Trust.

We continue to try to make the register more accessible to the general public with the launch last year of a new web portal which includes audiovisual content related to the challenges faced by people with MS in Scotland. We want Scottish people to read this report and get more of an understanding of MS and how it affects Scotland.

Over the past year the register has been the basis of several research projects which have been presented at national and international conferences. Research papers using data from the register have been published in good quality scientific journals and have generated media coverage from the BBC and the Herald newspaper. We have presented more details about this research by the lead author Dr. Patrick Kearns within this report.

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 our clinical coordinator, who has regularly visited all of us involved in data submission to ensure our continued commitment and enthusiasm. Thanks to Martin Paton our analyst who continually strives to ensure the data is meaningful to all. Thanks also to George Mowat-Brown who chairs the patient representative group (PRG) and provides feedback from this group to the steering group.

Importantly I must again thank the MS specialist nurses who continue to input data for the register. The numbers in this report represent individuals that the MS specialist nurses help look after and the individuals represented by these statistics are the reason that we are here. The time spent by the nurses collecting data 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.

Unfortunately my consultant neurologist colleague Dr Belinda Weller has not been able to contribute this year although she does follow the activity of the register. She has now retired from clinical work and is missed by both her patients and her clinical colleagues. Her role at the register has been central in the past and she has helped shape this high quality Scottish resource.

Dr. Niall MacDougall

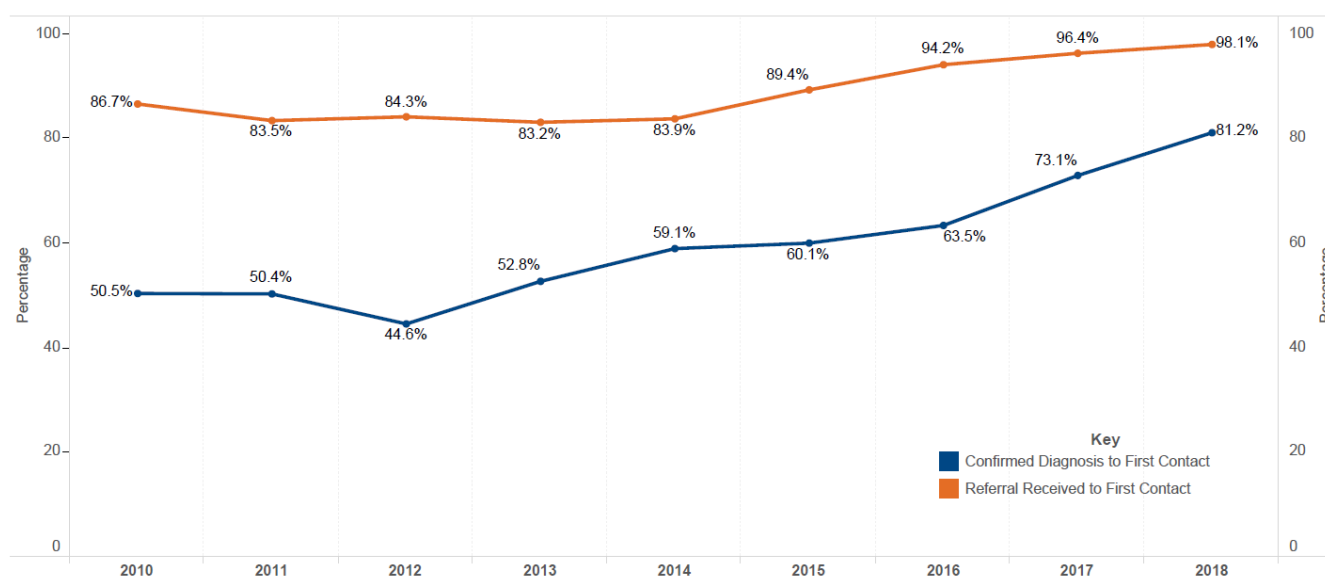
National Clinical Lead, SMSR Neurology

Highlights & Analysis

Members of the steering group have contributed the following analysis of the highlights of the 2018 data. More extensive data is available to view at

<http://www.msr.scot.nhs.uk/Reports/Dashboard/Dashboard-2019/Main.html>

Percentage of patients with a new diagnosis of MS contacted by a MS specialist nurse within 10 working days of confirmed diagnosis and percentage contacted within 10 working days from receipt of referral, Scotland.



This figure compares the National Clinical Standard (percentage of patients contacted by a MS specialist nurse within 10 working days following confirmed diagnosis) to the percentage of patients contacted within 10 working days once the MS specialist nurse has received the referral.

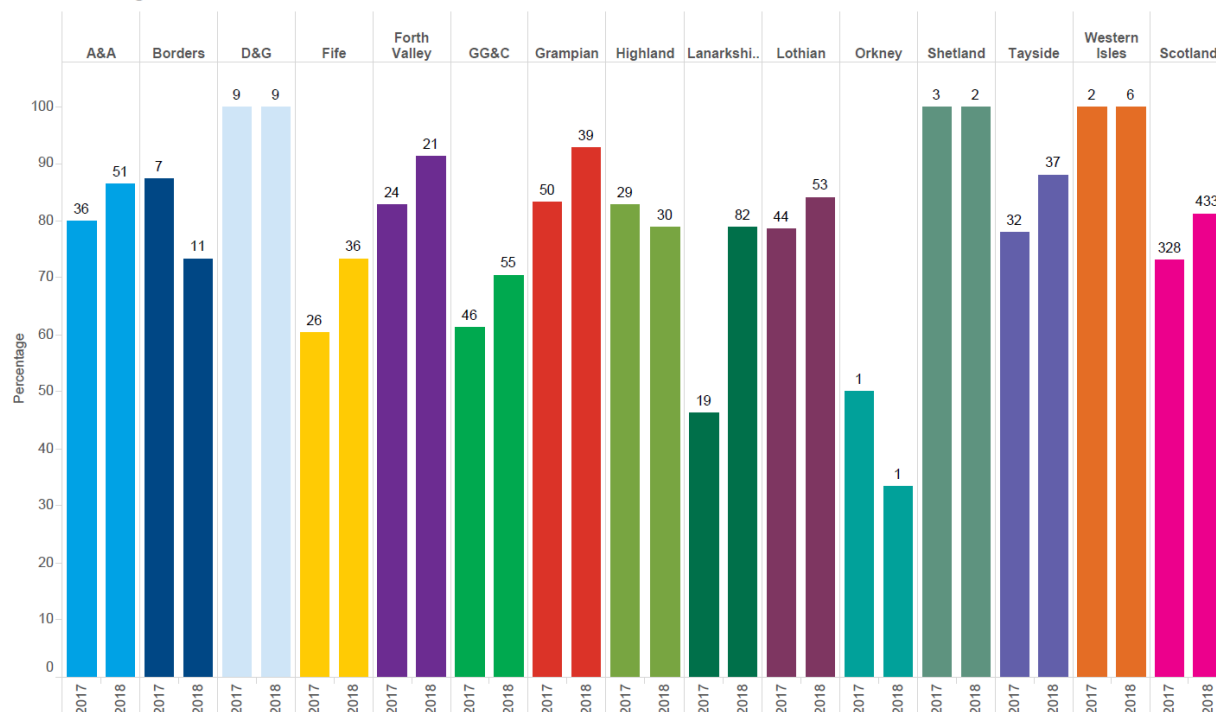
It is encouraging to note that performance across Scotland against the National Standard continues to improve from the recorded minimum 44.6% in 2012 to 81.2% in 2018 representing an almost two-fold increase in performance. There has been a continual improvement since 2012 with the most notable increase over the period 2016 to 2018 with a 17.7 percentage point increase.

Additionally, we continue to observe improvement in the percentage of newly diagnosed patients receiving contact from a MS specialist nurse within 10 working days of the nurse receiving the referral - peaking at 98.1% in 2018. The differences between these lines demonstrates the stage of the process between confirmed diagnosis and the MS specialist nurse receiving the referral. It is good to see the narrowing of both of these over the last few years.

Whilst it is welcoming to see performance against these measure increase we recognise that there is more that can be done. In particular, to reduce delays in the referral process which would further narrow the difference between these measures.

Percentage and number of people with a new diagnosis of MS contacted by a MS specialist nurse within 10 working days of confirmed diagnosis.

Figure 3a: Percentage and number of people with a new diagnosis of MS contacted by a MS specialist nurse within 10 working days of confirmed diagnosis.

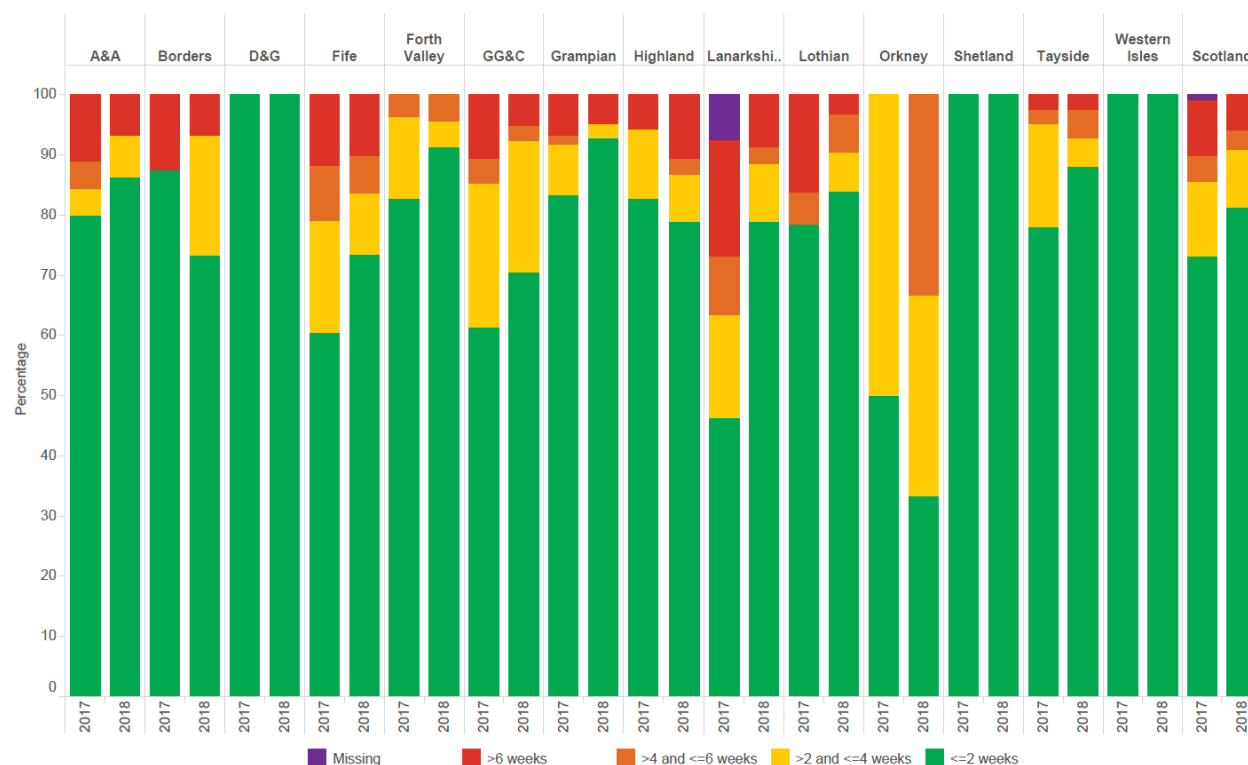


This figure shows the national improvement of National Clinical Standard 15.2 in 2018 increased to 81.2% from 73.1% in 2017. Standard 15.2 of the National Clinical Standards for Neurological Health Services (2009) states that following a diagnosis of multiple sclerosis “Contact with a Clinical Nurse Specialist is offered at diagnosis to patients with MS and contact is made within 10 working days of diagnosis”.

Whilst eight NHS Boards show improvement and three have maintained 100%, NHS Borders, NHS Highland and NHS Orkney have shown a decline in performance in relation to the national standard. NHS Orkney have declined from 50% to 33% from confirmed diagnosis to contact with the patient however these numbers are particularly low and from the point of receipt of referral the MS specialist nurse has achieved contact with the patient 100% of the time within 10 working days. On the occasions where the standard was not achieved this was due to a letter referral causing a delay in receipt of the referral.

NHS Grampian have improved from 83.3% in 2017 to 92.9% in 2018 and in this time have successfully implemented an electronic referral system to a generic email box for all MS specialist nurses supporting patients diagnosed at Aberdeen Royal Infirmary. Along with the email referral system NHS Grampian MS specialist nurses implemented a buddy system to cover leave for lone workers in Moray, Shetland and Orkney.

Percentage of people newly diagnosed with MS in Scotland, by number of weeks from confirmed diagnosis to first contact with a MS specialist nurse.



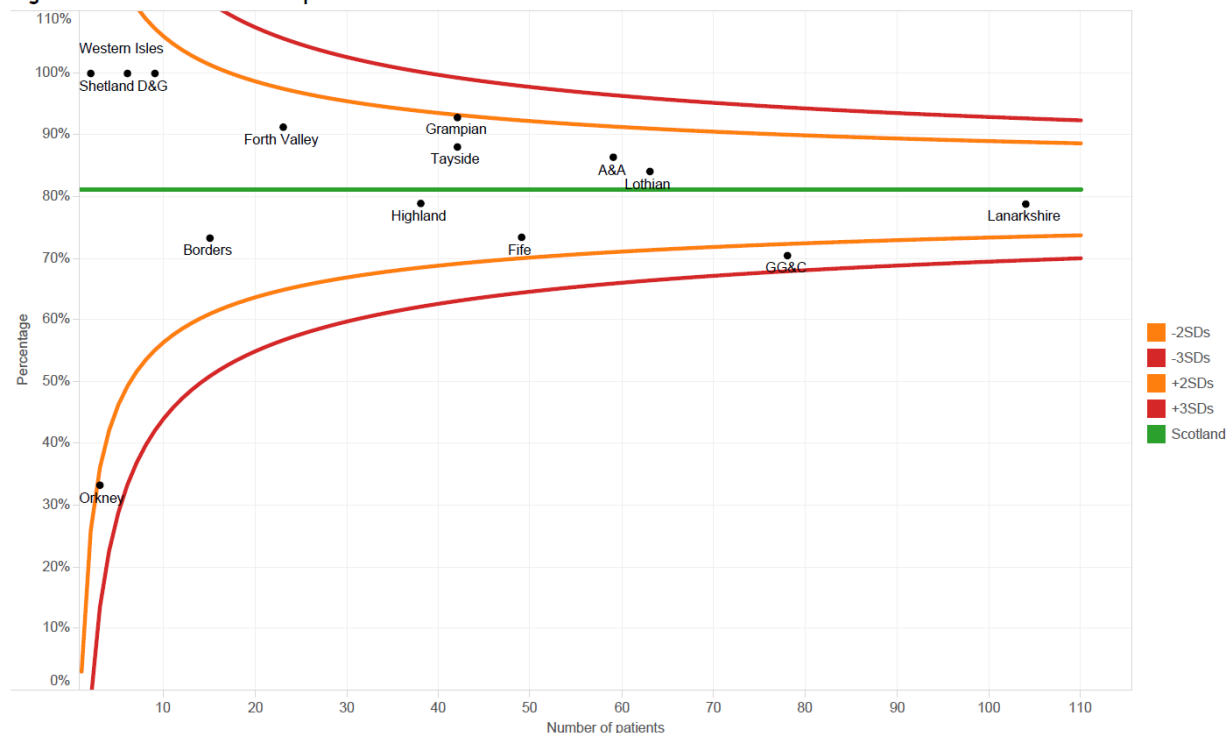
This figure demonstrates the time in weeks from confirmed diagnosis of MS and initial contact from a MS specialist nurse. It is positive to see that nationally patients waiting 6 weeks and more for contact with the MS specialist nurse following diagnosis declined from 9.6% in 2017 to 6% in 2018.

Where the standard has not been attained, 3.2% of patients were contacted within four to six weeks and 9.6% between two to four weeks.

There has also been an improvement in data capture due to the implementation of the electronic proforma. Since January 2018 all data have been collated and submitted by an electronic proforma and as this figure demonstrates there are no missing data recorded for 2018.

Funnel chart for compliance rate with National Standard.

Figure 5: Funnel chart for compliance rate with National Standard.



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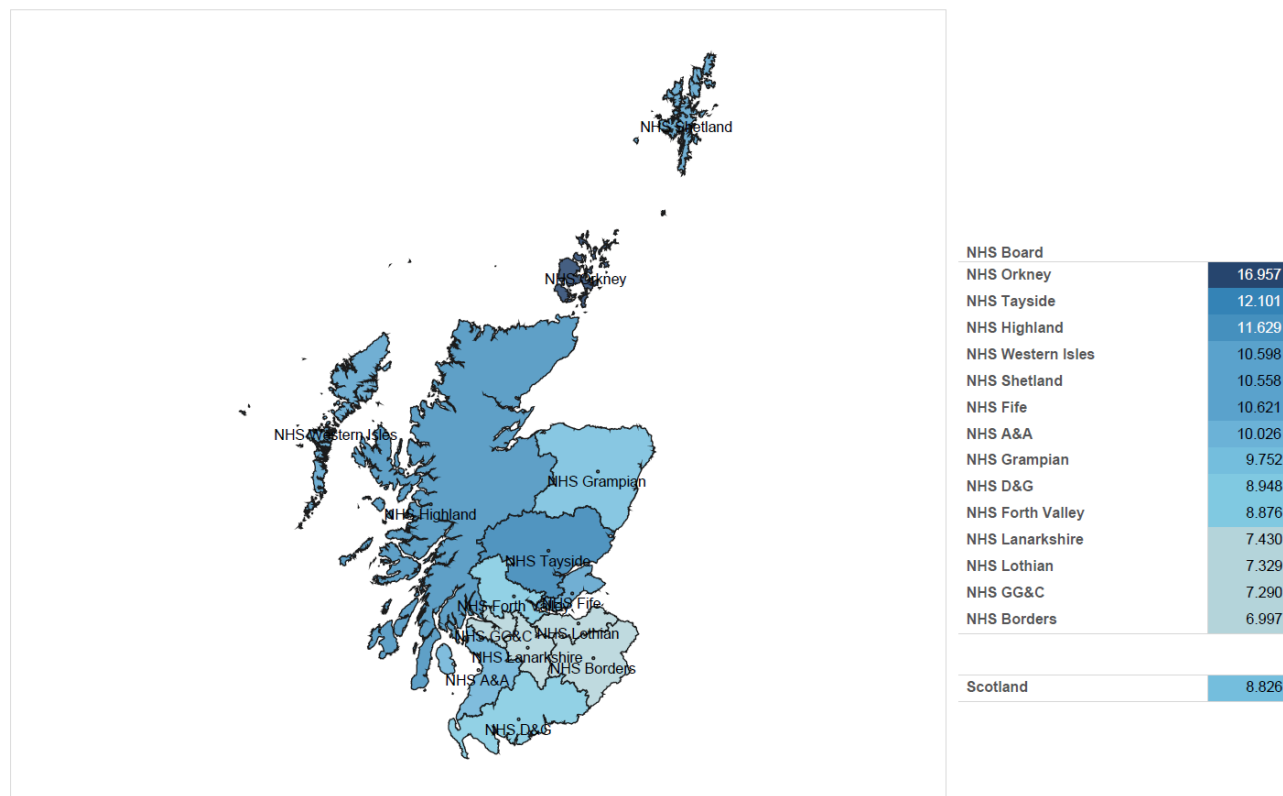
This year the SMSR has introduced funnel charts to examine the variation in compliance of the national clinical standard at NHS Board level against the national compliance rate.

Funnel plots include statistical control limits which are used as triggers for further action for Boards. These are set based on the range of differences in rates among Boards that would, in theory, be reasonably likely due to random variation alone. They are, however, based on basic statistical assumptions and are not necessarily indicative of an underlying problem of care. They act as pre-specified prompts, for further action from the Boards identified.

The first trigger, set at 2 standard deviations from the national average acts as an alert to Boards to clinically review. The second trigger, set at 3 standard deviations from the national average, is used to alert Boards that they are considered to be an outlier and are therefore required to investigate the issue and provide a formal response

Figure 5 shows that all NHS Boards except for NHS Orkney and NHS Greater Glasgow & Clyde are within the control limits. Both NHS Orkney and NHS Greater Glasgow & Clyde are over 2 standard deviations from the Scotland compliance rate.

Average annual incidence of newly diagnosed people with MS per 100,000 population, 2010-2018 data (by NHS Board of residence).



The 2010 - 2018 data show the overall average annual MS incidence is 8.83 people per 100 000 population in Scotland. The SMSR includes patients with a diagnosis of MS according to the McDonald diagnostic criteria. This is slightly higher than in 2010 - 2017 (8.64 per 100 000) and it is possible that the revised McDonald criteria first published in December 2017 could be contributing to earlier and more diagnoses of MS.

As per previous years the highest incidence rate of 16.96 per 100 000 is recorded in NHS Orkney and the lowest incidence rate of 6.99 in NHS Borders. The variation across NHS Boards persists. In their recently published paper Kearns et al suggest that latitude, environmental factors, vitamin D levels, local variation in services and other biologically risk factors in different regions may be important in contributing to this observation. This paves the way for future research and should inform service planning.

Investigations split by NHS Board (of diagnosis) and year of diagnosis.



As expected a brain MRI was done almost universally. A very small percentage of patients in NHS Grampian and NHS Lanarkshire have not had a brain MRI and the likely explanation is there may be contraindication due to pre-existing conditions. The spinal cord MRI was done in nearly 60% to 70% of the patients in the various NHS Boards. It is generally not done universally, but to facilitate diagnosis, or to confirm spinal cord relapse. Often coexisting cord lesions may not be registered unless patients have the scan, it may be useful practice to scan the spine for reference and monitoring. It is interesting that spinal cord MRI was done in all of the patients in the private sector.

As regards lumbar puncture, there does appear to be wide variation of practice, with nearly 90% practice in some NHS Boards and only 30% in others. Until the recent update of the diagnostic criteria, presence of cerebral spinal fluid (CSF) oligoclonal bands has not always been needed for diagnosis and therefore variable practice. As of the new diagnostic criteria, MS can be diagnosed at first presentation, on the basis of MRI scan and presence of CSF oligoclonal bands, and one would expect an increasing trend of lumbar punctures. In 2019 the SMSR has expanded the data collection to include oligoclonal bands in line with the McDonald diagnosing criteria.

Mary Wilson: Road to the Olympics

Paralympic Selection Journey

After playing para badminton for just under 2 years, doing well in the international tournaments and ending up at the end of 2018 ranked number 5 in the world in my category, I decided I would throw everything into the ring and attempt to be selected for the GB Team Paralympic Team.

This has meant, since the 1st Jan this year competing in international para badminton tournaments which started with Turkey, Dubai, Uganda and I have just finished in Canada. Unfortunately I had to withdraw from the Dubai competition as I seriously injured my ankle, but thankfully with a great physio it is now slowly on the mend.

Uganda was played in austere conditions with no air con in the hall and humidity of 89%. As you all know humidity/heat can affect MS and I really struggled with the heat and continual sweating. I managed to win silver in singles, mixed doubles and bronze in women's doubles but it did take its toll on my body.

The next tournament is in Ireland so much closer to home. I believe there will be at least 23 countries taking part. All trying to gain Paralympic points. Trying to be a full time athlete is extremely difficult as I can't train the same as a player who has an illness or injury that is more stable than MS. I train 3 times a week with a coach on badminton skills and should be training twice a day for an hour and a half. Morning is weights and stretches and afternoon Cardiovascular. This is impossible for me to do as I need to sleep after training and I would say at least half of the time only train once a day as I am too fatigued.

After Ireland is the World Championships in Switzerland and then Thailand/China back to back. There is still no funding for Scottish para badminton and so all the costs are down to me to pay. At this level it is a very expensive sport and certainly not all inclusive so I have set up a crowd funding page at https://www.justgiving.com/crowdfunding/mary-para-just-giving?utm_term=apBMXzApr to help.

However, I hope this inspires people to give it a go, in whatever sport they would like to try or are doing and the way I look at it is – Never say Never!

Improvements and Innovation

Alter-G

The Alter-G Anti-Gravity Treadmill, a machine normally used for rehabilitation of professional athletes like Andy Murray, Anthony Joshua and footballers at Manchester United & Chelsea, is also proving popular amongst MS groups in the North of Scotland.

Many people living with MS become inactive. This inactivity can result in lost muscle tone and weakness, poor posture alignment and trunk control, decreased bone density (and the increased risk of fracture) and shallow, inefficient breathing. Exercise is one tool to help with symptom management. The Alter-G allows the user to exercise at only a fraction of their own bodyweight, which makes mobility easier, helps strengthen muscles improve balance.

Originally developed by NASA, the premise is simple. Users are zipped into a pair of specialist neoprene shorts and a waist-high airtight bag which encloses the treadmill. The space around your legs fills with air, lifting you up, allowing you to exercise at a lower bodyweight, reducing impact and pressure on your joints, as you walk, run, and exercise. Gait re-education can also take place in a fall safe environment and it can be coupled with FES (Functional Electrical Stimulation) units, allowing users with decreased mobility to walk again.

“I was diagnosed with MS almost 10 years ago and my mobility has got progressively worse over the years. I started attending Move4ward in October 2018 and had weekly sessions on the anti-gravity treadmill. By December 2018 I had made significant progress towards becoming more mobile.

Unfortunately, however, in January 2019 I suffered a relapse which resulted in my mobility deteriorating again and me having to use a wheelchair full time. In just three months Dave and Jude have succeeded in getting me back on my feet and walking again with my crutches. I cannot recommend Move4ward enough. Dave and Jude are friendly and upbeat whilst maintaining an air of professionalism. I hate to think where I would be right now mobility-wise without their expertise and encouragement. Move4ward has been nothing short of a lifeline for me.” – Susan Shand.

Digesting Science

Ayrshire & Arran Multiple Sclerosis Service, Douglas Grant Rehabilitation Centre

Digesting Science is an exciting event to teach children, 6-12 years old, about Multiple Sclerosis. It breaks down learning about MS into key pieces of scientific information and is communicated in a simple and fun way. Digesting Science events aim to empower and equip young people with the knowledge to deal with issues of having a parent with MS. Children get the chance to try walking with heavy limbs, experience numb feet, and see what it's like to have blurred vision as is common in optic neuritis. There are also games that explain the importance of Vitamin D and the myelin that surrounds nerves.

Digesting Science was set up in 2013 by the Barts MS Research team at Queen Mary University of London. They identified the need to support parents when talking to their children about MS. The activities were developed by designers, Barts MS scientists and parents with MS to ensure that every activity is both factually correct and fun to complete. The project is regularly run in and around London, including Great Ormond Street Hospital. They realize that not everyone can reach their

events, so they developed kits and supporting material that can be sent out to anyone (an MS Nurse, a parent with MS, a physiotherapist) who would like to run an event in their area.

In Ayrshire we have held events at the Douglas Grant Rehabilitation Centre in January and March 2019. Families were identified at regular MS Review clinic appointments and invited along to a Digesting Science Event. Each event was facilitated by a variety of staff from the Douglas Grant Rehabilitation Centre, including Nursing, Psychology, Occupational Therapy, Physiotherapy, Dietetics and Administrative. Both sessions very extremely well received by all 6 families. Families were asked to complete a short evaluation afterwards. Feedback from both sessions included:

What did you get out of the event today?

- “More simple ways to explain to children.”
- “A lot of good information and had a lot of fun learning it!”
- “Left having understood everything and really enjoyed herself!”
- “Meeting other children in the same situation.”

What did you learn from the activities?

- “I learned quite a lot. I knew the symptoms but now I know why they happen!”
- “Learned more about bladder issues.”
- “Children now understand how I feel.”
- “I have taken ideas and tips on how to explain symptoms.”
- “Mum’s symptoms are common and normal!”

Do you think this event will help your family?

- “Yes, as the girls did not really have any knowledge at all.”
- “I do feel when they see me unwell they can think back to today and know why it is happening and not feel scared.”
- “My family can appreciate my daily struggles.”

We aim to run this event 2-3 times per year. If you would like to find out more about Digesting Science with the Ayrshire and Arran MS Service please telephone 01294 323029.

For more information contact: <http://digestingscience.co.uk/>

NHS Greater Glasgow & Clyde

There have been many exciting changes within the team at NHS GG&C. Dr Thomas retired and Dr Overell moved on to pastures new and our well known MS specialist nurse, Lynn Cherry has also retired. We would like to take the opportunity to wish them well and welcome Dr Paul Gallagher and MS specialist nurse Kate McGuigan to the team.

The NHS GG&C MS team have been exploring ways to decrease waiting time for patient appointments. We aim for people seeing the right person at the right time and being offered the most appropriate treatment using shared decision making. Taking the lead from Realistic medicine, we have tried to be innovative in our approach and developed protocols to improve efficiency. Where a patient’s condition remains stable the Clinical Nursing Service (CNS) offer support and advice therefore reducing waiting times for patients experiencing relapses who require consultant input.

AIMS Process

Working together with our colleagues in the Outpatients department, people living with MS are invited annually to participate in AIMS (assessment in MS) testing. This assessment utilises research based tools to assess cognition, upper body function, mobility and vision. The results are measured and should any changes be identified a referral can be initiated to the consultant for review.

The team have received positive feedback on the assessment with the benefits of a structured assessment being identified rather than being asked “How are you?” and another person commenting that “I feel that the team really care about how I am even though I am not on a treatment”. However it has also been identified that others have found the assessment challenging and do not see the benefit at this time.

It has provided the opportunity to share learning and professional development on the impact of living with MS for the team carrying out the assessment.

Venepuncture Clinic

Working together in collaboration with the Outpatients department team we have introduced a venepuncture clinic to provide a monitoring service for people undertaking disease modifying treatments (DMTs). This service offers more flexibility for patients to manage their appointments at a time that is most suitable for them. This service has improved patient safety, efficiency and effectiveness of nursing resources by reducing missed appointments.

Future Plans

Moving forward we are in the midst of a scoping exercise reviewing the nursing role to make our service more efficient and are currently developing a self-management tool for people living with MS to monitor their symptoms. We will be implementing the ‘Near Me’ service which was formally known as Attend Anywhere and featured in last years’ SMSR national report to improve accessibility to the CNS.

We plan to meet with all neurology consultants to facilitate the referral process to the CNS following a confirmed diagnosis. This should go some way to decrease time of referral to CNS as well as attaining the national clinical standard.

We look forward to an exciting year ahead, as more medications become available we are working in collaboration with the pharmacy department to explore ways of reducing waste as well as unwarranted variation in practice and outcomes.

Research

Patrick Kearns

Scotland has been known to have one of the highest rates of MS in the world for approximately sixty years. By using the first eight years of data collected by the Scottish MS Register we have been trying to study whether that risk is evenly distributed across the country – and we now think that it is not. The first part of this analysis has been published in the Journal of Neurology where we show that the incidence rate of MS varies up to three-fold across Scotland and that this seems in agreement with previous studies suggesting that these differences might be longstanding. Orkney has the highest rates, but the Tayside, Highland, and Grampian regions are all higher than would be expected by chance, Tayside having higher rates than Shetland, and all of these areas being significantly higher than the central belt or the borders. Dumfries and Ayrshire are intermediate areas. Even though across Scotland as a whole, MS affects women more than twice as commonly as it affects men, these differences in rates are so great that the risk for a man living in Tayside or Orkney may even be higher than for a women living in certain other parts of the country. The second aspect of this work, which is undergoing peer review at the moment and so is not yet published, attempts to look more locally than at Health Board areas to identify which towns or local areas have higher than expected rates (clusters). Also, by combining the data from the SMSR with the Scottish Index of Multiple Deprivation we are able to study whether living in an urban or rural area, or living in an affluent or socioeconomically deprived area, for example may be associated with risk. The hope is that this will yield clues which could help to identify risk factors for MS which could help us prevent the condition and better understand it to target new treatments.

MS Specialist Nurses: New To The Team

Kitty Millar – NHS Highland

Kitty's background is palliative care and practice nursing. In 2017 she gained the Queens Nurse award which is about providing excellence in communities. She has always had a keen interest in MS and other neurological diseases and was delighted to be appointed in the part time post as MS nurse specialist for Argyll and Bute. Kitty covers a large geographical area in which she provides education, specialist advice and assessment, support people with MS on disease modifying therapy and disease progression. I am also the MND nurse specialist for Argyll and Bute.

Emily Harrison – NHS Lothian

Emily is one of the MS specialist nurses who work within the Department of Clinical Neurosciences for NHS Lothian, which are based in the Anne Rowling Clinic, Edinburgh. Emily recently joined the MS nursing team after relocating from London. Emily has experience in managing MS across the disease trajectory, having worked as a MS specialist nurse in primary and secondary care from 2002. Emily also has experience as working as a Chronic Pain Specialist Nurse within NHS Lothian and is an independent nurse prescriber.

Kate McGuigan - NHS Greater Glasgow & Clyde

After graduating from Edinburgh University in 2001, Kate spent several years in neurosurgery and Intensive Care before becoming a Clinical Research Nurse through both the Edinburgh and Glasgow Clinical Research Facilities. Since 2011, she coordinated the MS Research portfolio in NHSGG&C, and was involved in the exciting start of drug trials for SPMS and remyelination therapies. She joined the MS Clinical Nurse Specialist team in NHS GG&C in January 2019, and is delighted to have the opportunity to work more closely with this motivated and engaged group of patients and clinicians.

Fiona Sneddon – NHS Fife

I have 14 years experience working within a specialised neuro rehabilitation unit. I feel privileged to have recently joined the MS Service within Fife Rehabilitation Service at NHS Fife.

MS Society

My MS, My Way: Tayside

Our new service My MS, My Way: Tayside is here for anyone who's been diagnosed with MS in the last five years and lives in Tayside.

The service provides information and emotional support to help people understand their diagnosis and explore ways to live well with MS. It includes:

- Support at MS clinics
- An information line
- Counselling
- Virtual Living Well with MS sessions
- One to one peer support (launching Autumn 2019)

We're run by the MS Society and the MS Therapy Centre Tayside, and funded by the National Lottery Community Fund and NHS Tayside Community Innovation Fund.

Contact us at 01382 938 082 or mymmsmyway@mssociety.org.uk. You can find more information at www.mssociety.org.uk/tayside-my-ms-my-way

Living Well with MS sessions

Our virtual and face-to-face sessions help people with MS connect and share experiences. They're a safe space where people can chat to others who understand what they're going through.

The sessions are run by a member of a MS Society staff and a volunteer with lived experience of MS. They explore common issues like managing fatigue, coping with stress, and communication with professionals. Each session is flexible to the needs of the people who attend and what they'd like to talk about.

Find out more at www.mssociety.org.uk/living-well-with-ms-events

MS Benefits Advice Service

Our MS Benefits Advice Service offers free advice to people affected by MS across the UK. You can get in touch with our MS Benefits Adviser by calling 0808 800 8000 or emailing msbenefitsadvice@dls.org.uk

The service is part of the MS Helpline, which gives emotional support and information to anyone living with MS. The MS Helpline is here Monday to Friday, 9am to 7pm (except bank holidays).

You can contact the MS Helpline on the number above or send a direct private message on Facebook messenger between 9am and 5pm Monday to Friday. We also have a confidential email service: helpline@mssociety.org.uk. So drop us a line and we'll get back to you within five working days.

Funding research to stop MS

Scientists are working on three ways to tackle MS: stopping the immune damage, promoting myelin repair and protecting nerves from damage.

We're the largest charitable funder of MS research in the UK. In Scotland this includes:

- The MS Society Edinburgh Centre for MS Research, which aims to speed up the discovery of treatments for people with MS. Researchers are focusing on causes and mechanisms behind progressive MS, along with testing new ways to slow or stop progression.
- We're co-funding a landmark phase 3 trial exploring simvastatin for secondary progressive MS. MS-STAT2 will involve 1,180 people at sites across the UK, including one in Edinburgh.

Find out more about research at mssociety.org.uk/research

MS Trust

An MS diagnosis can be devastating for both people with MS and their loved ones. You may feel lost, alone and uncertain of the future. But you don't have to deal with these feelings by yourself. The MS Trust is here for people from the moment of diagnosis, and throughout their journey. We're here on day one, and every day after.

Enquiry Service

Whether you have recently been diagnosed or want to know more about a symptom you are experiencing, our friendly and knowledgeable enquiry service team are here to help. Our service is confidential and if we can't find the answer, we can direct people to someone who can. You can get in touch with us in whatever way suits you best. You can call us for free on: 0800 032 3839; email us on infoteam@mstrust.org.uk; or send a message to our Facebook page (www.facebook.com/mstrustuk).

Trusted information

At the MS Trust we believe in providing the best help and support so people with MS can take control of their MS. We produce practical, evidence based information, both online and in print, which is clear and helpful. All our books and online resources are written by our team of MS experts and accredited by the Information Standard, so you know it's information you can trust. Our information covers a whole range of topics, from lifestyle tips to MS symptoms; explaining MS to kids to drugs and treatments.

Find our website at <https://www.mstrust.org.uk>.

Training and funding MS health professionals

MS nurses and other specialist health professionals are crucial to helping people with MS deal with their diagnosis, consider treatment options and adjust to living well with MS. As well as providing vital support and training to MS specialist teams up and down the country through our development module for new nurses and annual Conference, the MS Trust funds MS specialist nurses in the areas across the UK where they are needed most. To date, we have funded seven new MS specialist nurses, who in turn have provided care and support to 3,612 people with MS. This is just the start. Our nurse programme will continue at pace to identify and support the need for new MS nurses. At the same time we will work with the employing organisations to ensure the sustainability of these roles.

As well as our Specialist Nurse Programme, last year we also launched our Advanced MS Champions programme, which funds specialists to provide guidance and coordinated care for some of the UK's 40,000 people with advanced MS, a group of patients who too often miss out on specialist MS care. We have already funded three advanced MS Champions in Swansea, Salford and Cumbria, and aim to have a further three Champions in place at sites across the country over the next year.

This will benefit large numbers of people in those areas living with the complex and often devastating symptoms that characterise advanced MS.

Service development is another important part of our work with MS health professionals on the frontline, and we are dedicated to providing the support MS teams need to improve and develop their service, and ensure that the needs of people with MS are being met. For example, with our help, the team at Leicester has created new community and hospital based clinics and an improved phone service to enable them to reach even more people with MS.

You can find out more about our work with MS health professionals at <https://www.mstrust.org.uk>.

Staying active

Regular, moderate exercise is now known to be an important part of maintaining good health and wellbeing for people with MS. There is evidence that it can help with many MS symptoms, and also with general quality of life. We have a number of resources to help people with MS stay active, including...

Pilates circuits (<https://www.mstrust.org.uk/life-ms/exercise/move-it-ms-pilates-jo-pritchard>) - Neuro-physiotherapist Jo Pritchard presents a series of Pilates exercises designed for people with MS. They can be done in seated or standing positions and you can follow along at home.

Build your own exercise routine (<https://www.mstrust.org.uk/life-ms/exercise/build-your-own-exercise-routine>) - Explore our series of simple exercises to help your balance, posture and strength.

Move it for MS: Accessible exercise with Mr Motivator (<https://www.mstrust.org.uk/life-ms/exercise/exercise-videos>) - Mr Motivator presents a series of exercise videos designed for people with MS. These videos are suitable for all abilities, and include exercises to improve your balance, strength and flexibility without leaving your home.

Supporting young people

MS can be tricky enough to get your head around as an adult, so imagine how difficult it must be for a child or teenager to deal with all the uncertainty it can bring. MSTV, the MS Trust's dedicated YouTube channel for young people affected by MS, can help you make sense of it. It features fun, engaging and informative videos on a whole range of topics, everything from managing symptoms and taking care of your mental health, to talking to your friends about MS.

You can subscribe to MSTV at: www.youtube.com/mstvuk.

MS Revive

Contributing to National Action Plan Implementation

Extending support to the most vulnerable – including those isolated by location, disability or for economic reasons – ensuring they are socially connected and helping them to remain in work are key national priorities.

Over the past year, Revive MS Support has contributed to this with the phased roll-out of our tele-health programme, Access to Revive MS Support (ARMSS), providing easy access to our clinical professional services for anyone affected by MS, using the Attend Anywhere platform and requiring only a smartphone or pc.

Our newly appointed Clinical Manager, Margaret Campbell, tasked with driving forward this Programme and with the implementation of our new Clinical Strategy, commented:

“Our Strategy, to 2021, is innovatory in terms of the multiple levels and types of care for people with MS that it offers, both at the local level and nationwide. This includes our flagship ARMSS Programme that reaches right into the most isolated communities where clusters of people with MS live. Amongst the benefits of this include: bringing targeted specialist care into people’s homes, opening peer support channels and providing access to group therapeutic interventions targeting the symptoms of MS that most effect daily life: chronic pain, fatigue and anxiety/depression.

The Strategy also includes the scoping of a City Centre Outreach – with 80% retiring within 15 years of diagnosis, mostly due to cognitive difficulties (which are treatable and manageable) new approaches are needed to get support to the hidden population with MS who work in our cities. Initial indications suggest that time-limitations, lack of employer awareness and limited access to services present major barriers to support.

The prospective need for this outreach emerged during our participation in The Pilotlight Programme, with Morgan Stanley, showing the importance of collaboration with stakeholders in generating new ideas and approaches to get people the care and support they need. If feasibility is shown this new form of outreach would be scalable to cities nationwide.

Combined with provisional plans to extend our existing outreach provision, currently covering three locations, to other areas, using a new satellite outreach approach and working with the network of Specialist Nurses to maximise local support, we believe that these initiatives will reach many more people in need of support, making a strong contribution to the National Implementation effort.”

Alongside this, we have recently introduced a neurologist-supported series of experiential workshops for children, parents and carers touched by MS, known as Digesting Science, enabling them to understand the challenges that their loved ones live with, day-to-day. Coupled with our impending launch of a Falls Prevention Programme, supported by the installation of the first purpose-built multi-surface therapeutic walking area for people with MS in Scotland (adjacent to our Centre), addressing the significant fall (and fracture) risk associated with the condition, we are making an important contribution to the changing landscape for people with MS.

Case Study

Caroline Logan –providing integrated, holistic, care, combined with strong social support, for as long as it is needed (used with permission, compiled 1st July 2019)

“For me Revive is a lifeline. If you don’t know MS, you won’t get it. People get it here. Everything we do is individualised for us. The whole experience leaves me with a smile on my face.”

Diagnosed during her second pregnancy in 1981, Caroline has RRMS. She was one of Revive’s first ever clients. Her initial symptoms, severe numbness and pins and needles, have never really left her.

She returned to work as a Carer when her sons went to school, becoming a Service Manager for adults with dementia.

However, she suffered a major relapse 3 years ago (2016) and had to take early retirement.

Her Consultant and MS Nurse at Queen Elizabeth University Hospital recommended she return to Revive. She says, “Maryhill was like a treatment centre. This place (our new Centre in Govan) is different; there are many more opportunities to get support and to share all the different life experiences.”

Caroline now receives five types of rehabilitative support through our MS Centre in Glasgow as well as self-managing her symptoms at home (where possible), with our guidance. This has greatly improved her quality of life e.g.:

- She receives very regular MS Specialist Nurse support – this led to her recent enrolment in a trial at Glasgow Caledonian University to address debilitating bowel problems. The trial changed her life, giving her considerable relief, day-to-day. With the support of our Specialist Nurse she now self-manages her symptoms using a non-invasive massage belt;
- Physiotherapy – she receives spinal manipulation for neck, shoulder, leg and hip pain, has a home exercise programme designed by Revive to self-manage spasticity and pain between sessions, and attends weekly gym exercise classes:

“There’s a real social element, we have all become good friends. We all make time for each other and are going through it together”.

MS Mid Argyll

We have had a very busy year as ever at the centre. We have had three of our volunteers train with versus arthritis to deliver tai chi, We now deliver two tai chi sessions a week to our members and members of the local community to come and join in. This is also getting rolled out across some of the rural communities covered through the outreach service.

At the centre we have been working closely with adult learning to help up skill some of our member's we have had many work shops running from make up lessons, sewing workshops and Spanish cooking. This has been a fantastic recourse for us and a great learning opportunity for so many.

We have started a new session on a Friday afternoon called the 'brain gym' this is bringing people together to play games, learn news skills and spend time with other people. We have lots of different things available for people to try on this day and have volunteers on hand for some one to one support. Most of the people coming along live on their own or do not see many people in a week so they have been really enjoying the company of others while doing a cross word or playing dominos, we see lots on smiling faces on a Friday afternoon.

We continue to raise awareness of MS and the work that we do here at the MS Centre Mid Argyll, last year we delivered training, awareness days and fundraising in Jura, Islay, Glasgow university and Inveraray to name but a few. Through both the centre and the outreach services we are working closely with other local group to make sure people are getting the best support they can from what is on in their local community. The centre offers a text support service as well as online support for people who can not access the centre or the outreach service easily. The text service has been received well by everybody who is using it, This can be used for appointment reminders, positivity texts and simply checking in on people.

From Your Boards

NHS Borders

In 2017 87.5% and in 2018 73% of patients were contacted by the MS Specialist Nurse within 10 working days of their diagnosis of MS.

We have identified that there is a delay in communication between the consultant Neurologist and the Specialist MS Nurse. The two causes for this delay have been identified as being due to annual leave/ sickness on the part of either the consultant Neurologist or the Specialist MS Nurse and a delay in typing and sending of paper correspondence.

We have therefore changed our practice, and all new diagnoses will now be communicated by email to the Specialist Nurse. This eliminates any delay inherent in the dictation, typing and sending of paper correspondence. As the service is run by one Consultant and one Specialist nurse, we cannot eliminate the possibility of delay through absence.

In the years 2017 and 2018, 100% of patients diagnosed with MS in the Borders were contacted within 10 working days of receipt of referral by the MS Specialist Nurse.

NHS Grampian

We have a generic email that consultants use to email referrals to MS nurses. The Aberdeen, Elgin, Orkney and Shetland MS nurses are included in this email so when on leave the other nurses will pick up the emailed referrals. We started using this about a year ago. Clinic letters are electronically passed to the nurses as well.

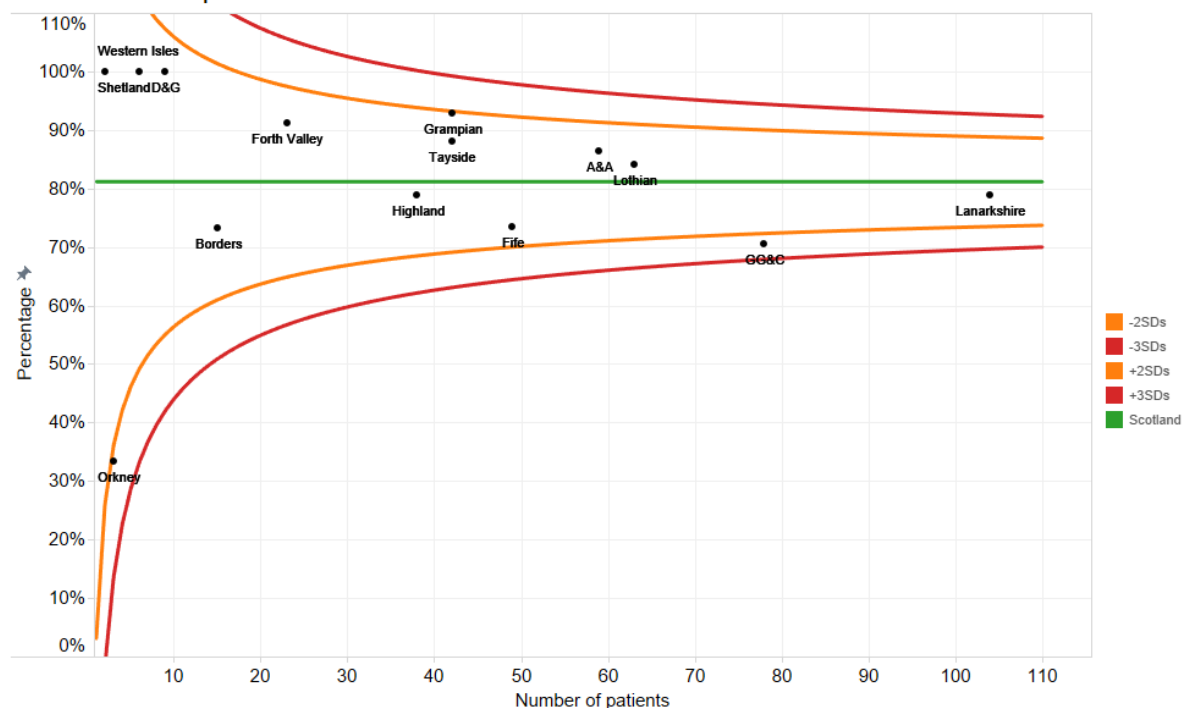
From graph B3.1 it looks like we improved our rates of response from 2017 to 2018.

Like all other health boards we do have patients that are diagnosed elsewhere, also in private healthcare and are sometimes reported late.

Over the last 2 years we have started having regular (8 weekly) team meetings that include the MS nurses and two consultants where we discuss service provision and the logistics of looking after patients with MS.

Outliers

Funnel chart for compliance rate with National Standard.



Note: These figures exclude paediatric patients; patients that have refused contact with MS specialist nurse and cases for which we hold a missing year of diagnosis.

As mentioned within the highlights and analysis section within the report this year the SMSR has introduced funnel charts to examine the variation in compliance of the national standard at NHS Board level against the national compliance rate. The funnel chart indicates that all NHS Boards except for NHS Orkney and NHS Greater Glasgow & Clyde are within the control limits. Both NHS Orkney and NHS Greater Glasgow & Clyde are over 2 standard deviations from the Scottish mean and have provided the following responses

NHS Greater Glasgow & Clyde

In relation to Standard 15.2 and NHS Greater Glasgow and Clyde's performance noted for 2018 at 70.5%. A further 21.8% of Greater Glasgow and Clyde patients had contact from an MS clinical specialist nurse between 2-4 weeks of diagnosis. 2.6% of patients had contact between 4-6 weeks; and a further 5.1% had contact made after the 6 weeks. The service has reviewed the complex pathway for patients and identified improvements to address this level of performance. Whilst we note there have been ongoing challenges for MS specialist nurses in achieving this standard, the process has changed in the last 4 weeks, and the MS consultants are now referring patients via the Generic MS Nursing mailbox. This has already seen a local improvement in performance and we anticipate further improvement over the coming weeks and months.

NHS Orkney

NHS Orkney currently sits between the 2nd and 3rd standard deviation.

Diagnosis takes place by our consultant neurologist in Aberdeen. Unfortunately clinic letters from the consultant neurologist regularly are not received by the MS specialist nurse in NHS Orkney until after the 10 working days target. Hard copy letters continue to be posted despite having a facility to email via a dedicated email box. Our MS specialist nurse is extremely diligent and continues to contact patients on the day a letter is received.

Moving forward the MS specialist nurse is now to submit a clinical incident report (Datix) every time NHS Orkney are informed of new diagnoses after the 10 working days target so this can be recorded and reported to the consultant neurologist.

Due to small numbers (three patients total, two where NHS Orkney were not notified of diagnoses until after 10 working day target) results in our data showing a significant impact on achievement percentage.

Agreed Actions 2019:

No.	Action	Responsible	Completed
1	MS specialist nurse to submit clinical incident report for every letter which is received after the 10 working days target.	MS Specialist Nurse	In Place
2	Consultant neurologist reminded of requirement to email an update of Orkney patients' diagnosis to agreed generic email box to allow us to ensure 10 working days target is achieved.	MS Specialist Nurse	Consultant notified, to monitor
3	Consultant neurologist administrator contacted to ask for assistance with ensuring neurologist complies with Action 2.	MS specialist nurse	Complete

Agreed actions from previous year:

No.	Action	Responsible	Completed
1	Set up generic email box to receive letters confirming diagnoses	NHS Orkney IT / MS specialist nurse	Complete

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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. 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:

- Mary Wilson who was willing to share her experience and inspire many with her achievements
- 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;
- The Patient Reference Group and those who generously gave their time and welcomed the coordinator to attend their patient groups, who 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 Ailsa Grandison, Richard Buchanan and Grant Ritchie for their support and guidance.

For more information - www.msr.scot.nhs.uk/

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Further Information

Further information can be found in the full report on the [Registry website](#) or on the [ISD website](#).

The next update for this publication will be September 2020.