



**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

During the year in which we celebrate 70 years of the NHS in Scotland it is fitting to reflect on and honour the hard work of NHS staff, including nurse specialists, providing support to people living with a range of conditions, such as Multiple Sclerosis (MS), across hospital and community settings.

I therefore welcome this year's Scottish Multiple Sclerosis Register (SMSR) report setting out the achievements and progress made during 2017, which includes a further increase both in the percentage of newly diagnosed patients seen within 10 days from a diagnosis from 63.6% to 75% and those seen by a MS specialist

nurse within 10 working days from referral from 93% to 96.7%. This represents a rising trend in performance over the past few years and demonstrates how our additional investment in the Specialist Nursing and Care Fund has enhanced provision and improved outcomes for those requiring specialist care.

This report also highlights how our vision for the future of healthcare in Scotland, is starting to be applied in practice, based around the guiding principle of person centred care. We are at the beginning of a transformational journey and recognise that while progress is being made, we must continue to intensify our efforts to drive improvements. 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, such as those living with MS, to make informed choices about their care.

After all, our aspiration is to build on what our society does to understand and support others to live their lives well. Something which will resonate with Mary Wilson, featured on the report's front cover, who, since her diagnosis of MS in 2004, has overcome many challenges to participate and win four medals at the Invictus Games and is now training for the 2020 Paralympics.

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.

Dr Catherine Calderwood
Chief Medical Officer



1 Welcome

I am honoured to introduce the eighth annual report of the Scottish Multiple Sclerosis Register (SMSR). This report is the result of a lot of work by a lot of people. The register has been collecting data related to new diagnoses of MS since 2010. While MS is an important and relatively common disease in Scotland we have not had precise data on the numbers of Scottish people affected by the disease. The register is improving our understanding of the epidemiology of MS in our country. Over a longer period of time this will help the Scottish Government and the NHS plan the care need the people affected by MS have and deserve.

Data have now been collected on 3692 people with a confirmed diagnosis of MS, 425 of whom received a diagnosis in 2017. 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 paper based proforma. The data are securely stored within the Information Services Division (ISD) of NHS 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 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. The steering group works with staff from ISD who coordinate the register nationally and who collate and validate the results. We are lucky to have ISD as a national resource. The intelligent use of data is difficult and the data analyst role is often undervalued. We need experts to make sure that we use numerical data correctly and we don't make mistakes.

There has been an effort over the last year to improve the way in which the register works. A new web electronic data collection form has been created in the hope that this will make data easier and also facilitate the validation of data at the time of entry. We hope this will further improve the quality of data in the register while continuing to 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.

Beyond this we are aiming to make the register more accessible to the general public with the creation of a new web portal that will include audiovisual content related to the challenges faced by people with MS in Scotland.

Good quality research has been generated by the Scottish MS register and a paper on the relationship between latitude and MS incidence in Scotland has been submitted to a high quality journal and will hopefully be published this year.

The register continues to serve as a barometer for the quality of clinical services for MS. The data from NHS Lanarkshire in 2017 highlight the previously publicised issues with specialist nursing provision at that time and I'm pleased to report that an increased number of nurses has now been improved to improve the management of the MS case load of over 1200 patients. NHS Lothian continue to have only 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.

Unfortunately, Dr Belinda Weller, my co-chair for the register has been unable to take an active role this year. She has been an active clinical lead and clear source of direction for the register over the years and we continue to build upon her vision.

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. Chrissie has been looking at other ways in which the register can be used to improve the care of people with MS across Scotland. She has been looking at developing a standardised nursing assessment document for patients with MS as well as exploring the possibility of developing further mechanisms to improve the standard of MS nursing care. Thanks also to George Mowat-Brown who chairs the patient representative group (PRG) and provides feedback from this group to the steering group.

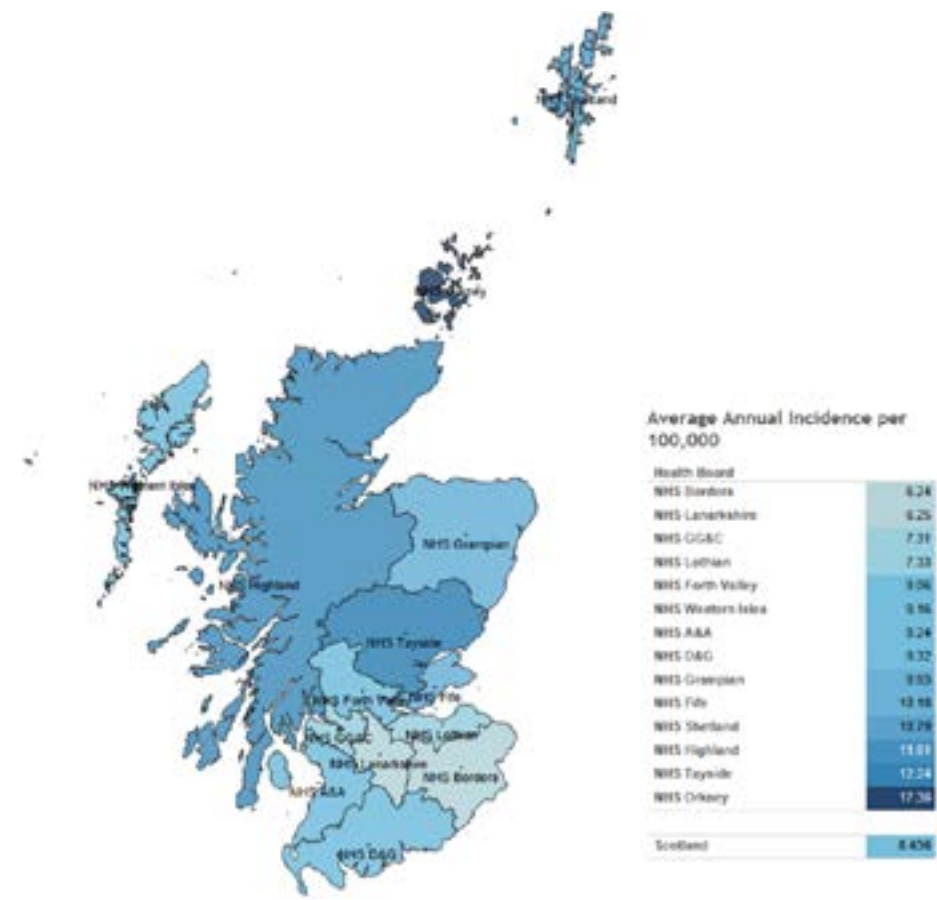
In particular I wish to thank the MS specialist nurses who continue to input data for the register. As we continue with budgetary constraint in the NHS everyone is facing increasing demands on their time and energy. None the less it is more important than ever that we continue to collect accurate data 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. Niall MacDougall
National Clinical Lead
SMSR Neurology

2 Highlights & Analysis

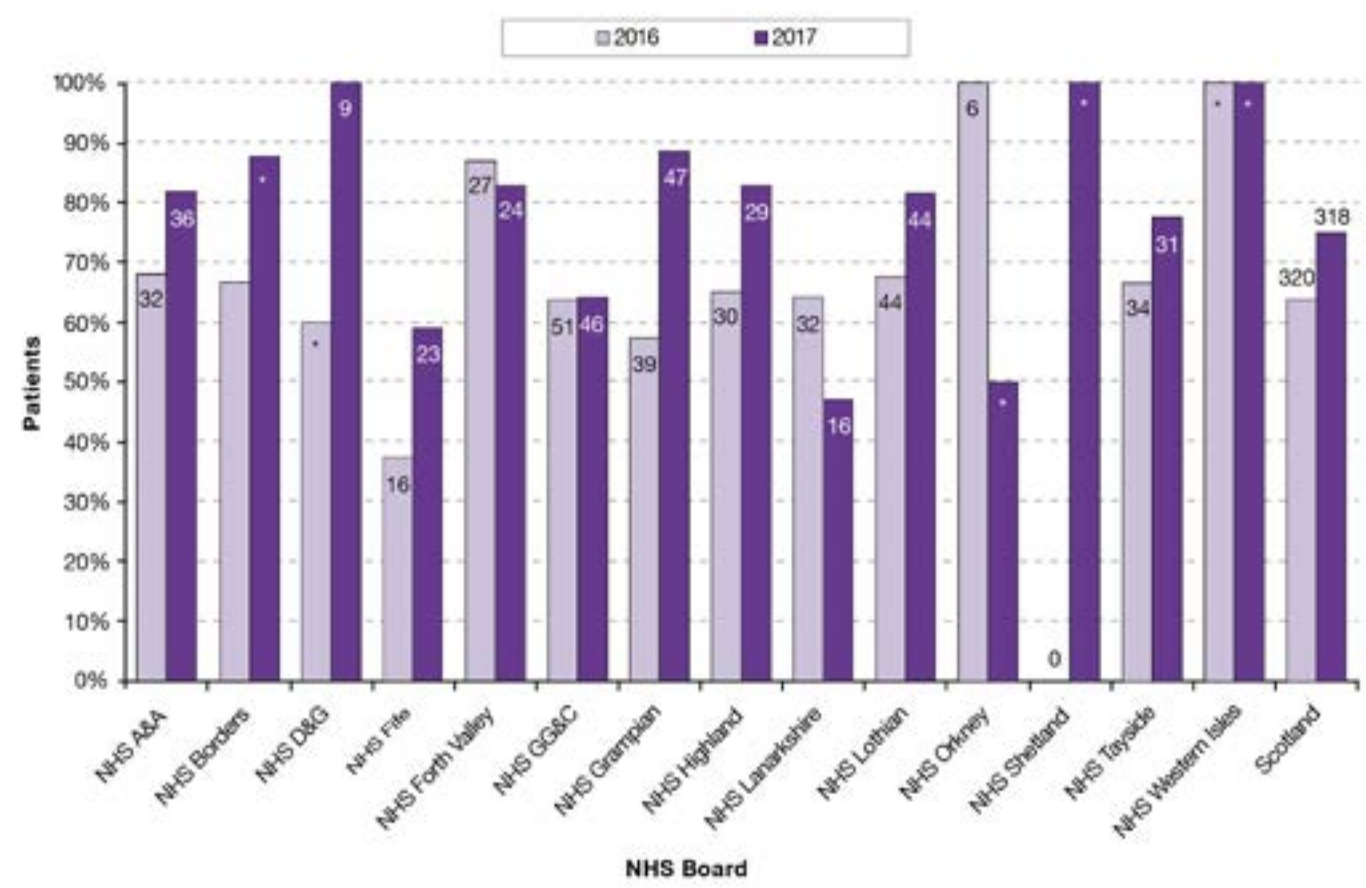
Members of the steering group have contributed the following analysis of the highlights of the 2017 data. More extensive data is available to view at [here](#).

A2.1: Average annual incidence of newly diagnosed people with MS per 100,000 population, 2010-2017 data (by NHS Board).



Nationally across Scotland we have observed an average annual incidence rate of 8.64 cases per 100,000 people. Across Scotland, incidence rates vary considerably, ranging from 6.24 cases per 100,000 people in NHS Borders to 17.36 cases per 100,000 people in NHS Orkney, in line with the well recognised relationship between latitude and incidence rate. The association between MS incidence and latitude continues to be an area of active research, along with the possibility of links between vitamin D and MS incidence. The MS register collects incidence of MS confirmed by the McDonald criteria which have recently been reviewed and do not include cases of clinically isolated syndrome or “possible or probable” diagnosis.

B3.1: Percentage and number of patients with a new diagnosis of MS contacted by a MS nurse within 10 working days of confirmed diagnosis, 2016 and 2017 data.



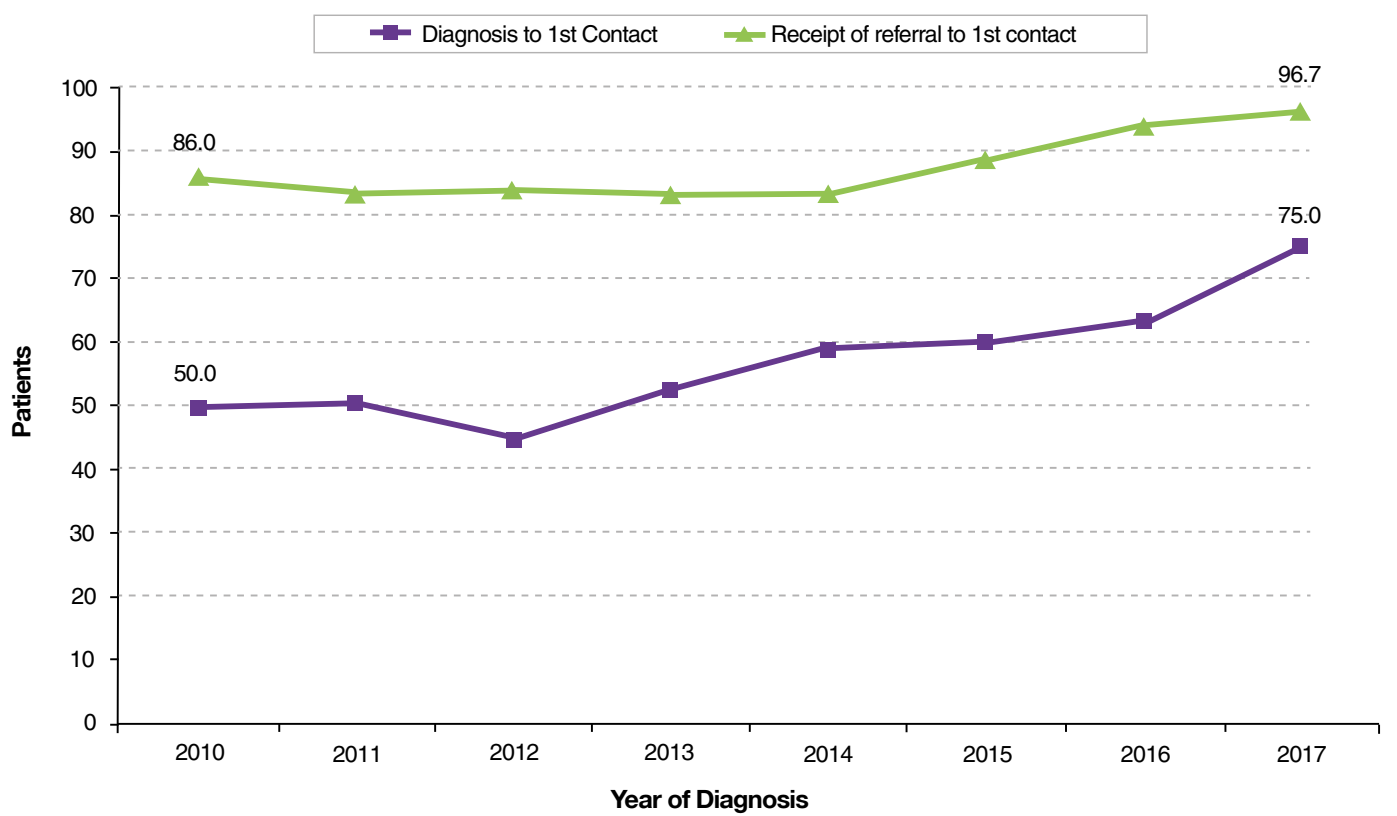
Note: Following ISD Statistical Disclosure Control Protocol, any cells with count values of 4 or less have been redacted in order to protect the confidentiality of potentially personally identifiable information.

B3.1 is a key quality indicator for MS patients and nurses across Scotland. The diagnosis of MS can be very distressing and swift expert support is essential for people affected by MS.

MS Specialist Nurses are expected to contact anyone given a confirmed diagnosis of MS within 10 working days of the diagnosis. As B3.1 shows there has been an improvement in 9 out of the 14 centres. Nationally 75% of patients were contacted within this time period in 2017 compared to 63.6% in 2016 – an increase of 11.4 percentage points (B2.1). While there is still clearly work to be done in some areas in order to achieve this key quality indicator for every patient this improvement is promising.

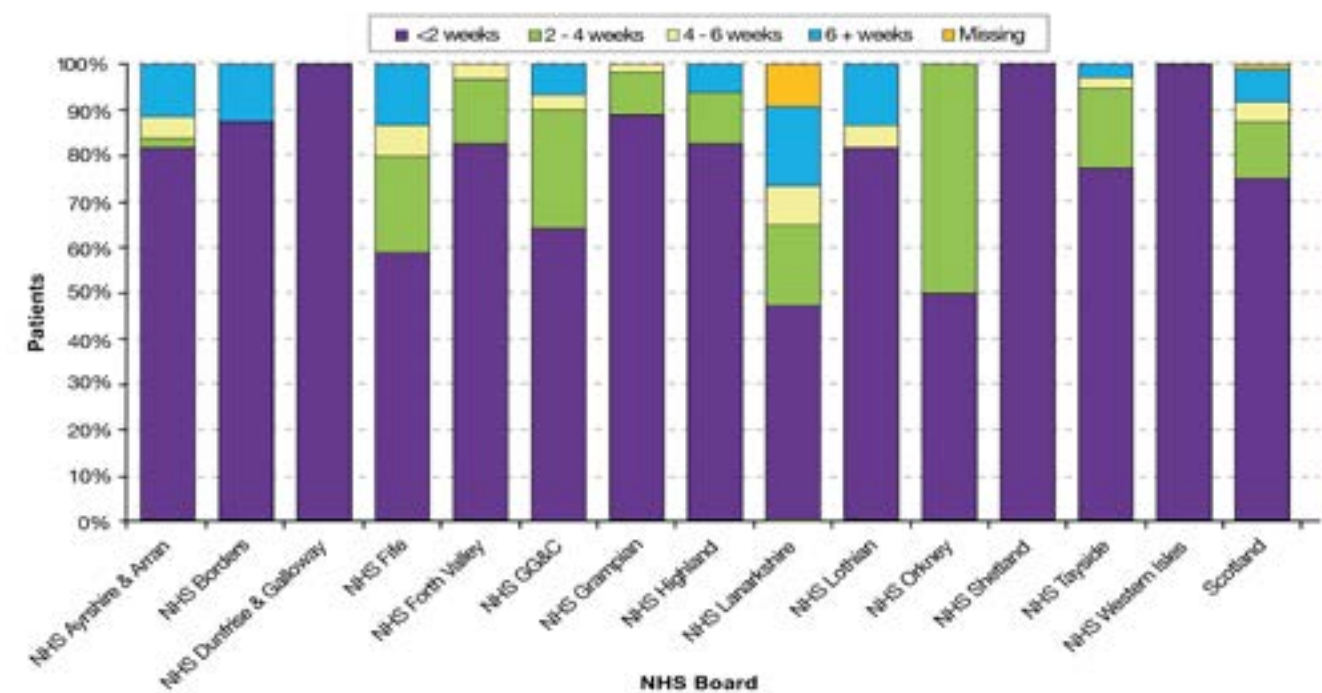
For the 5 Health Boards that have not improved over the past year there may be local reasons as to why this has happened. The central SMSR team are working with colleagues in Health Boards across Scotland to review the referral process and it is hoped that improvements to this in addition to increased staffing levels in some areas will lead to an improved performance. Performance against this key quality indicator will continue to be monitored locally and it is hoped that there will be further evidence of improvement in the next report.

B2.1: Percentage of patients with a new diagnosis of MS contacted by a MS nurse within 10 working days of confirmed diagnosis and percentage contacted within 10 working days from receipt of referral, Scotland, 2010-2017.



B2.1 demonstrates a comparison between percentage of patients contacted by the MS Specialist Nurse following diagnosis within 10 working days (National Standard) and percentage of patients contacted once a referral has been received within 10 working days. 75% of cases met the target after diagnosis and 96.7% met target after the MS nurse received the referral. There is a delay between diagnosis and referral received by MS Specialist Nurse. This would suggest that improved referral pathways suitable for individual MS centres need to be developed and the central SMSR team will continue to work with boards to enable this improvement.

B4.1: Percentage of patients newly diagnosed with MS in Scotland in 2017, by NHS Board and number of weeks from confirmed diagnosis to first contact with a MS nurse.



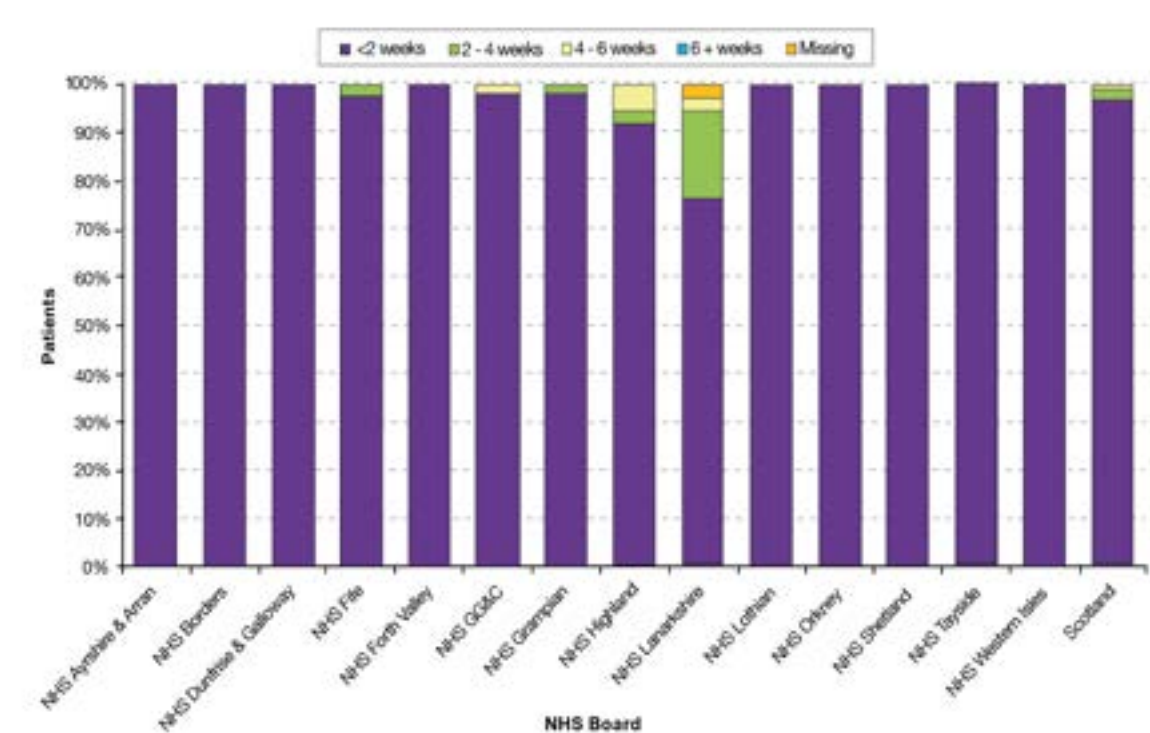
B4.1 shows the time taken for an MS Specialist Nurse to make contact with a person newly diagnosed with MS. In Scotland as a whole 87% of patients are contacted within 4 weeks of receiving a confirmed diagnosis of MS which is encouraging, however this is still below the standard of care expected for every patient of being contacted within 10 working days of confirmed diagnosis. Nationally for 31 individuals, there was more than a 6 week delay from time of diagnosis until contact from the MS Specialist Nurse.

NHS Lanarkshire is currently achieving the national standard for 47.1% of patients, which is below the national average of 75%. This is primarily due to staffing issues during 2017 which have now been resolved. It is therefore anticipated that there will be an improved performance in 2018 as NHS Lanarkshire have appointed a new team of MS Specialist Nurses.

Whilst NHS Orkney has only achieved the national standard for 50% of those with new diagnoses this is primarily due to a small number of patients receiving a confirmed diagnosis.

NHS Greater Glasgow & Clyde explored the cases where the national standard was not attained and report that the vast majority of delays are due to administrative processes They suggest that a solution may be in the introduction of an electronic referral system perhaps via TrakCare itself or perhaps a referral mailbox similar to that currently in use by NHS Lanarkshire MS Specialist Nurses.

B6.1: Percentage of patients newly diagnosed with MS in Scotland, by number of weeks from receipt of referral to first contact with a MS nurse, 2017 data.

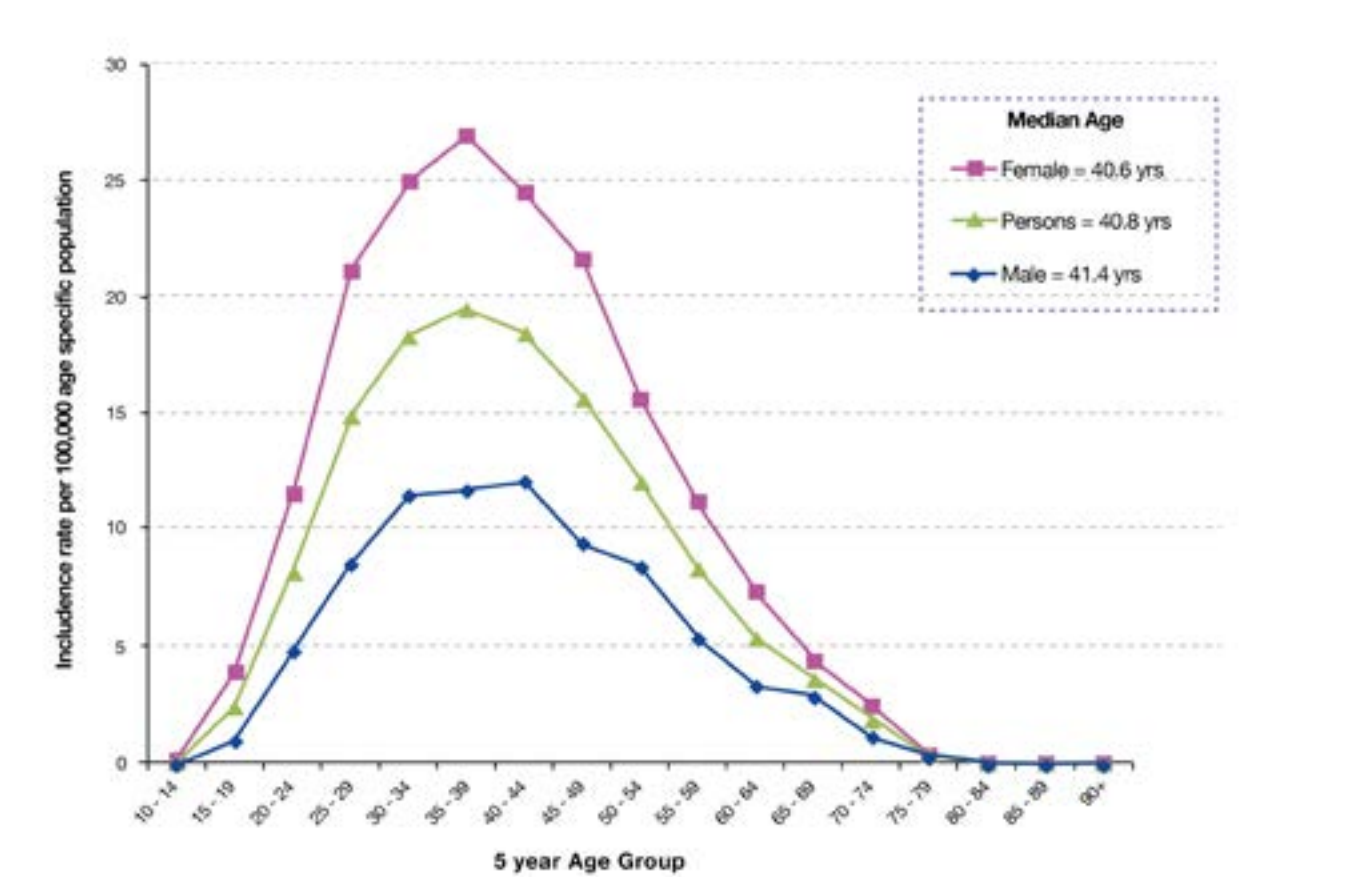


For a MS Specialist Nurse to make contact with a patient they need to have received a referral from a neurologist confirming the MS diagnosis. B3.1 and B4.1 show the time taken for a MS Specialist Nurse to contact a patient after diagnosis, but B6.1 is also important as it highlights delays in the process that may be a result of delays in information about new cases reaching MS Specialist Nurses.

96.7% of patients are contacted within 10 working days of a MS Specialist Nurse receiving a referral. The longer delays highlighted by the earlier charts are due to other factors in the system, for example, delays in initiating a referral and administrative systems. The central SMSR team are working with colleagues in NHS Boards across Scotland to review referral processes and instigate change for improvement to reduce delays in the process, for example by using email referrals. The central team collaborated with NHS Dumfries & Galloway to refine the data collection process, where the MS Specialist Nurse now completes the incidence form in collaboration with the patient at the clinic following confirmed diagnosis. This has resulted in an improvement of attaining the standard from 63% in 2016 to 100% in 2017.

As noted above, the longer delays seen in NHS Lanarkshire are considered to be due to staffing issues in 2017 and it is anticipated that an improvement will be seen in 2018 as this issue has been resolved.

A3.1: Average annual age-specific incidence of patients newly diagnosed with MS in Scotland per 100,000 population, 2010-2017 data (by gender).



A3.1 illustrates the age distribution of patients with a new diagnosis of MS in Scotland between 2010 and 2017. There are few new diagnoses among people under the age of 20 years.

From the period 2010 - 2017 the median age of all patients was 40.8 years and for females it is 40.6 years and for males 41.4 years demonstrating that females tend to be diagnosed at a younger age than males. It is clear that the age distributions for males, females and both combined are not symmetric but are actually skewed to the right. This means that the incidence rate is higher in later life than in the younger years. It is also apparent that the risk of MS is higher in women compared to men.

Multiple sclerosis significantly affects economically active age groups in Scotland and people continue to be diagnosed with the condition well into their 70's. The burden of MS on Scottish patients in different age groups provides important data for development of health policies and service planning. In older patients progressive disease and multiple comorbidities may limit treatment options

A1.1: Number and incidence rate of patients newly diagnosed with MS by NHS Board of residence, Scotland, 2010-2017.

NHS Board	Year of Diagnosis															
	2010		2011		2012		2013		2014		2015		2016		2017	
	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
NHS Ayrshire & Arran	17	4.6	28	7.5	34	9.1	36	9.7	33	8.9	36	9.7	47	12.7	44	11.9
NHS Borders	8	7.0	7	6.1	7	6.2	7	6.1	7	6.1	7	6.1	6	5.2	8	7.0
NHS Dumfries & Galloway	12	7.9	16	10.6	15	9.9	25	16.6	17	11.3	13	8.7	5	3.3	9	6.0
NHS Fife	28	7.7	28	7.7	33	9.0	40	10.9	34	9.9	53	14.4	44	11.9	39	10.5
NHS Forth Valley	17	5.7	23	7.7	25	8.4	26	8.7	28	9.3	38	12.6	32	10.5	29	9.5
NHS Grampian	54	9.6	49	8.6	61	10.6	64	11.0	52	8.9	59	10.0	68	11.6	53	9.0
NHS Greater Glasgow & Clyde	94	8.3	83	7.3	83	7.3	84	7.4	76	6.7	98	8.5	80	6.9	72	6.2
NHS Highland	36	11.3	24	7.5	30	9.4	39	12.2	46	14.3	40	12.5	47	14.6	36	11.2
NHS Lanarkshire	48	7.4	30	4.6	46	7.1	29	4.4	26	4.0	64	9.8	50	7.6	34	5.2
NHS Lothian	60	7.3	54	6.5	50	5.9	74	8.7	67	7.8	78	9.0	65	7.4	54	6.1
NHS Orkney	5	23.6	*	23.3	5	23.2	*	13.9	*	9.3	*	9.2	6	27.5	*	9.1
NHS Shetland	*	17.3	6	25.8	*	4.3	*	4.3	*	8.6	0	0.0	*	12.9	*	13.0
NHS Tayside	42	10.3	42	10.2	57	13.8	51	12.4	59	14.3	61	14.7	52	12.5	40	9.6
NHS Western Isles	*	18.1	*	7.2	*	10.9	5	18.2	0	0.0	*	3.7	*	7.4	*	7.4
Scotland	430	8.2	397	7.5	450	8.5	484	9.1	449	8.4	550	10.2	507	9.4	425	7.8

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

A1.1 presents the number of patients newly diagnosed with MS in Scotland for each year since 2010 by NHS Board of residence. There has been considerable fluctuation in the number of patients diagnosed each year ranging from the minimum of 397 cases in 2011 to a maximum of 550 cases in 2015. The number of newly diagnosed patients has fallen since 2015 but it is too early to know whether this trend will continue.

It has been hypothesised that there may exist a negative correlation between population density and incidence rate. This would perhaps explain as to why the islands, for example NHS Orkney, have a significantly higher incidence rate than more densely populated areas.

Due to some NHS Boards such as the Islands having a small number of people newly diagnosed with MS the incidence rates show much more variability when compared to the larger NHS Boards. For example, if the background population remains static, going from 1 to 3 people newly diagnosed would result in a 200% increase in incidence rate whereas an increase from 50 to 55 would only result in a 10% increase in incidence rate.

3 Mary Wilson: My War Against MS



I am 54 years old and had a career in the British army as a psychiatric nurse for 20 years. This included 4 Operational tours, one being in charge of the Field Mental Health Team Afghanistan in 2008. After tests in 2004 I was told in the most inhumane way by a doctor who just said “oh yes, you do have MS” and that was it, appointment over.

After crying for a day I decided it was just not happening to me. I was not going to be that person. I started training for 10k races. I also started climbing Munro mountains with my partner. These are the 283 mountains in Scotland above 3000 feet. It took much blood, sweat and tears, plus the termination of many midges along the way over a 10 year period to conquer these mountains. We climbed some of the mountains with ropes and walking for days to wild camp before even starting to climb. When I did my first one, I thought, I will never manage another one, but never say never! I got used to falling over, my fatigue and muscle weakness and the pain. It was all worth it.

I was Medically Discharged from the army in 2012 and I received an email asking if I would be interested in trying out for the Invictus Games. I remember watching people practicing the shot putt and discus and thinking, “I could do that” and started training myself in my dad’s back garden. However, the better I got the more flower pots got annihilated! I was selected for the GB Invictus Team and was honoured to be selected as the only female captain for the sport of Field Athletics. I won 4 medals in swimming and 2 in field athletics.

After the Invictus Games I felt like I was in a black hole. I could not let MS beat me and my stubborn defiance gave me a kick of reality and pride. I had a word with myself - do I just want to lie down and give up, or do I want to show what people with MS can do. I took up Lawn Bowls and won silver in the Scottish Disability National Championships.

In 2016 I took up Para badminton. I had played when I had been a child and had really enjoyed it. Little did I know I would be playing for Scotland 4 months later at my first international in Spain.

Since then I have visited many countries and medalled in all internationals. I am very proud to say I am a serious contender for the 2020 Paralympics in Tokyo and am No 4 in World Rankings.

Unfortunately, there is no sports funding for para sport and I have had to use my War Pension and Disability Living Allowance to pay for all costs as I am unable to work anymore, but I don’t regret it.

What I am trying to say is, never give up on your dreams, no matter how hard it is and no matter how small you may think your dream is. If it is getting up in the morning, putting a sock on, dressing yourself, managing to make a cup of tea or a small walk, then that is fantastic. Those are your Munro mountains. Don’t measure your worth by what other more able bodied people can do. As my favourite song goes by Heather Small, “what have you done today to make yourself feel proud”!

Mary Wilson

4 Steering group and patient reference group

Steering Group

The Register has its own Steering Group reporting directly to the Clinical Priorities team at the Scottish Government and also to the Clinical Outcome Measures for Quality Improvement (COMQI) group. It provides strategic direction and clinical input to the Register team, to optimise the use of the data. All information pertaining to the steering group is available at www.msr.scot.nhs.uk/About/steering_group/index.html

Patient Reference Group

The SMSR has an established Patient Reference Group which was set up by the Scottish MS Society prior to the establishment of the SMSR to ensure that the views of patients and their carers were influential in the formation of the SMSR.

The Patient Reference Group comprises a group of people with a confirmed diagnosis of MS drawn from various parts of Scotland. Some members attend with their carers whose views also contribute to the discussions. The Patient Reference Group ensures that the Register represents a wide range of views and concerns of people with MS and their carers and is a forum where its members can participate and guide the SMSR to focus on what matters to them.

The chair of the Patient Reference Group is also a member of the SMSR Steering Group and acts, with the Clinical Co-ordinator, as an interface between the two groups. If you would like to know more about the patient reference group please contact [Chrissie Watters](#), clinical co-ordinator. The [terms of reference for the patient reference group](#) are available on the MSR Website.

5 Patient's Voice

What Matters To Me

10 tips to living well with MS

1. A radar key is a large, conspicuous, silver-coloured key that opens more than 9,000 accessible toilets in the UK. Further information can be found at: <https://nks.directenquiries.com>
2. CEA card The Card enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema. The Card is also one way for cinemas to make sure they look after their disabled guests. If you require an adjustment to visit a cinema because of your disability, cinema staff should make them for you whether you have a CEA Card or not. Apply at: <https://www.ceacard.co.uk/apply>
3. Contact the DVLA so that they are aware of your diagnosis. Most people with MS will still be able to drive but it is your responsibility to inform the DVLA.
4. Contact your local authority and apply for a Blue Badge. Even if you don't drive-it is individual to the person, not a vehicle, so is helpful if out with relatives, support staff, etc.
5. Join any of the disabled organisations like Disability Equality Scotland, Disability Information Scotland, Glasgow Disability Alliance, MS Revive, MS Society and the MS Trust etc. They provide magazines, newsletters and a wealth of information on many things available for disabled people across Scotland.
6. Contact Rowling Care at the Anne Rowling Centre to be involved in their research projects. Contact details under Research section of report.
7. Apply for your disabled travel card. The card is great individually, but the Companion card can be especially helpful to let a carer or relative travel with you free on buses or get a discount on train fares. It can also be a card to identify a visual impairment-helpful for many things like free travel on trams. It can also be used as photographic ID as it is SG verified.
8. Look after your mental health and do not be afraid to ask for help at any stage. It is good to chat about your concerns and how you feel. Find someone who you trust and who will listen to what you have to say.
9. Speak with your neurological team and develop a treatment plan as there are many effective DMT's. They will be able to advise you on treatment options and alternative methods to control symptoms.
10. Speak with your manager at work, tutor at college or teacher at school about your diagnosis. They will be able to offer support in relation to occupational therapy referrals and adjustments at the workplace. Multiple Sclerosis is recognised in The Equality Act (2010) to allow for time away from the workplace to attend appointments.

Many thanks to all the people living with MS who compiled this list and for sharing your knowledge and experience in living well with MS. You are all an inspiration.

6 Improvement and Innovation



Mhairi Coutts

The virtual treatment room is now a fully implemented and successful service we offer to clients. The 'Attend Anywhere' platform has allowed us to expand our reach beyond the Glasgow and West of Scotland area as we now have clients living in Dunoon and Stornoway.

Virtual clinic is to enable people to access services remotely for a variety of different reasons, if they have no transport and find it difficult to make appointments, if they are housebound, if working and find it difficult to get time off for clinic appointments or if they live in rural areas. Any person with MS can participate or indeed a relative/carer of that person with MS can also take part.

We are currently the biggest user of Attend Anywhere, a web-based platform that helps healthcare providers offer video call access to services, and have been asked to supply demonstrations and provide case studies for a number of organisations.

Mindfulness has proved to be one of our most popular therapies for clients through the virtual clinic. We have received extremely positive feedback from this, and we are looking toward further development because of the response. We are planning to introduce group sessions providing more cost and time effective methods of support.

Revive MS Support first virtual consultation user, Evelyn said:

“Fantastic service. Mhairi has been my MS Nurse throughout my journey and I panicked when she was no longer in that position but after having a video consultation on my smartphone I realised I can retain contact without having to be mobile. Wonderful service. Thank you so much.”

We also currently provide access to MS Specialist Nurses, counselling and Speech and Language Therapy. Our staff members are continually becoming more comfortable and better experienced at using this technology. This is very promising for the future as clients from more diverse locations will be able to access Revive MS Support and the wonderful therapies we offer.

The progress we are making with this project is not only benefiting clients from further away but those with busy schedules or who are unable to travel easily to our centre. We feel this is a positive move for the future of our organisation.

Mhairi Coutts
MS Specialist Nurse
Improvement Fund
Improvement Hub (ihub)
NHS Western Isles

NHS Western Isles Patient Held Record

The nursing staff in NHS Western Isles identified a need for a patient held record, with patient centred forms, that could then be left with the patient in the home. Following a scoping exercise digital pen technology was implemented. This allows for forms to be completed with the patient where the data is then transmitted from the pen, via Bluetooth to a smart phone. A PDF is created and stored within the patient's electronic record on SCI. Allowing the original document to remain with the patient. This efficiency saving measure negates the need for the nurse to update records at the base following home visits. The new system has been reviewed with evidence that patient facing contact has already increased by over 50% since full implementation.

Currently NHS Western Isles is in the process of implementing a full electronic patient record called eMRec. Phase 1 of this process involves scanning all paper records including hospital, community and AHPs. On completion of Phase 1 a GP extract will be incorporated into the patient record. In eMRec there will be a direct feed from all GP practices in NHS Western Isles which will allow clinicians to view current medications, allergies and alerts, relevant medical history and current medical conditions. Finally the system will allow for diagnosis based ordering of investigations for Labs and Radiology.

Morse

Our other pride and joy at the moment is the implementation of Morse. There was a need for a system to support primary care and AHP clinicians that would free them of their administration burden. After examining current systems there was collaboration with the PAS supplier, who had already spoke of an interest in developing a system to support community teams. They collaborated with the community team to ascertain the requirements and core functionalities for a new system to ensure it was fit for purpose.

Morse was identified as a solution and implemented with success. Morse is a mobile platform that allows community staff to access, download and use patient information from the backend systems while working within the community. It will link in with NHS Mail diaries, allow messaging between clinicians and other agencies, give the capability to send and receive SCI Gateway referrals, and a host of other functions that the brilliant development team at Cambric are working on. This system will upload digital forms, eMRec etc and bundle it into a mobile office that allows the teams to download securely each day and really revolutionise community nursing and healthcare.

Teams using Morse are seeing a reduction of roughly one hour per day, per clinician time previously spent on administration tasks. The system is beneficial in terms of safety and directly improves patient care especially delivering care out of hours where the nurse has no prior knowledge of the patient details. The nurse is able to retrieve patient information from the Morse system using an iPad to deliver appropriate care and prevent the patient having to recount their history.

All paper proformas have been digitised by the supplier and are all available within Morse. Data fields can be pre-populated, images can be uploaded and data can be shared quickly and securely. NHS Western Isles Dietetics team are now fully digital on Morse and are reporting a 40% reduction in administration tasks.

Florence

Telehealth is a communication system that uses text messages to help patients and their health professional monitor and/or manage their medical condition more closely. The monitoring system is called “Florence”, sometimes referred to as “Flo” for short. Telehealth can be used for many reasons such as:

- monitoring the effects of new treatments
- monitoring the effects of stopping treatments
- to remind or encourage the patient to do something to take care of themselves
- identifying flare-ups of the condition to ensure effective treatment can commence promptly
- identifying reasons why the condition might not be well controlled.

Florence communicates by text messages to and from a mobile phone. It will work with any mobile phone or network able to send and receive text messages. All texts to and from Florence are free.

Telehealth does not replace all appointments. Patients will still see their health professional when required. The NHS Western Isles Telehealth monitoring service has been funded by a Scottish Government initiative called Technology Enabled Care (TEC) which aims to increase the number of people receiving Telehealth at home. Florence is not an emergency service. If urgent medical assistance is required then patients contact the appropriate service.

The MS Nursing service has utilised this to support and monitor patients requiring pelvic floor exercises and it has been beneficial in sleep monitoring in conjunction with Fitbits. This system has provided data for consultants on the mainland which enabled treatment plans and advice on how to manage sleep issues in people living with MS preventing patient travel.

Due to fact that there are numerous DMT’s which all require individual maintenance regimes “Flo” is able to send reminders to ensure patients attend blood monitoring and attend appointments minimising the risk of complications during treatment. Since the implementation of Florence it has shown that by receiving reminder texts that are tailored to the specific treatment protocols patient compliance was recorded at 100% in 2017-18 compared to 75% the 20016/17.

Moving forward the next progression for “Flo” is the launch a symptom tracking and relapse pathway. This will mean that patients who sign up to this will receive a weekly text that corresponds with the MS relapse pathway.

Beam

[Watch the BBC Alba video of the BEAM in action.](#)

BEAM is a telepresence robot. This has been utilised in the home of a patient with a young family to reduce risk and stress by supporting their partner/carers to be able to maintain daily routine i.e. work, school etc

7 Glasgow School of Art

Backpack: Personal Data Store

What if all your personal records, including your relevant personal health and care records were held in one place that you control?

Design researchers from The Glasgow School of Art worked together with a technology company (Mydex CIC) and a health professional (Dr. Jamie Hogg, NHS Grampian) to explore and develop the Backpack idea with people living with Multiple Sclerosis (MS) and with health and social care staff. People living with MS were identified as highly knowledgeable co-design participants, due to the complex and progressive nature of the condition, requiring many different interactions with public services.

The aims of the project were to explore how people living with MS would like to manage their personal information in order to improve the experience of accessing services, and understand the potential of the Backpack to support health and care professionals to deliver more integrated and person-centred care. This summary describes the Experience Labs’ activities on the project, and shares our findings and the ideas we collaboratively developed for the Backpack.

What did we do?

We held a focus group with people living with MS to gain insight into current experiences of living with MS, in particular the challenges of and strategies for managing personal information and accessing support.

The first Experience Lab brought together people living with MS to map some key moments of data sharing, before each participant created a paper version of their Backpack using a specially designed tool. Working collaboratively with a designer, they explored what types of information they would want to store, and how they would want to organise, share and secure the information.

In the second Experience Lab, health and social care professionals mapped the many possible interactions a person living with MS may have with health and care services, and tested paper and online versions of the Backpacks made in Lab one. Finally we discussed how access to person-owned data stores would change the way they currently work.

Experience Labs

Experience Labs were developed by The Glasgow School of Art’s Innovation School. They offer a safe and creative environment where researchers, businesses, civic partners and service users can collaborate to find innovative solutions to the health and care challenges facing our society. They are the core element in the Digital Health & Care Institute (DHI), one of the Innovation Centres funded by the Scottish Funding Council.

Experience Labs use a co-design approach and emerging design research methods to engage with partners and participants, who are encouraged to share their own experiences. Real-life practice is often replicated to allow new technology, services, processes and behaviour to be trialled rapidly to gather feedback from end users.

What did we discover?

Both people living with MS and health and care professionals were very positive about the concept of the Backpack, and saw how it could be used to improve communication and make services more person-centred.

Supportive people and services

We learned some general qualities people living with MS value from the people and services that support them. Services should be orientated around their personal goals and needs, and should seek to offer convenience to make everyday life easier. People valued services and places that felt safe and welcoming; and professionals who showed understanding about the challenges of living with MS, and were knowledgeable about the people and services that could help.

Access to health information

Participants would value the ability to access their own health information, with equitable access to the information their health professional holds about them. They also told us that health professionals working in different services or health boards do not always share health information, and suggested that the Backpack would allow them to ensure their health professionals had access to all the relevant information. While they might not want to see lots of medical jargon, they would want to see their high level test results and have the ability to access the detail if required, e.g. to share with a health professional in a different region.

“I want them all to have access to the same information but they don’t always, within different systems...” - *Mini-Lab Participant*

“I would be empowered to answer the Doctor’s questions.” - *Lab 1 Participant*

“The thing about health information for me is availability trumps confidentiality” - *Mini-Lab Participant*

Security

Participants were pragmatic about the benefits of having access to a shareable digital data store, versus the risks. The Backpack must make use of familiar and trusted security measures to overcome concerns about security.

Person-centred

A key value of the Backpack is the ability to reflect the personality and interests of the owner. This concept was embodied in the paper backpacks made in Lab 1, where “fun stuff” or personal interests were a feature of all, and for one particular participant this became the centre of their Backpack.

This supports the need to ensure the Backpack can accommodate this information to facilitate everyday life and activities. Health and care professionals would also value this information, supporting them to understand what the person enjoys and tailor their care to their aspirations.

In addition the Backpack should be adaptive and anticipate the needs of person as their health and care requirements change.

Design Concepts

Four design concepts were created in response to key insights or challenges.

Insight 1

The health and care system is very complex and it is often challenging to find the person or service that can help.

Concept 1: Mapping Interactions

The Backpack should map the care interactions around the person, providing high-level information to make visible the complex network of professionals supporting the person. This would allow the person, their family and their health and care professionals to see the care that is currently in place, providing contact details and a short summary of the support they are providing. This could be shown as a circle of care or on a timeline.

Insight 2

People living with MS described having to recount their ‘story’ every time they connect with a professional or service, which is emotionally draining and time-consuming.

Concept 2: Health Story

A ‘Health story’ would provide a space within the Backpack for the person to share their story in their own words, using video or written narrative, supported by key dates and facts.

Insight 3

People living with MS described the challenge and emotional cost of navigating complex systems to find the right information, people and services. Eligibility criteria and forms seem to be deliberately confusing, deficit based and require significant energy to complete, which is already in short supply for people living with MS.

Concept 3: Smart Form Filling

The backpack could gradually fill up with information as the person completes forms and could automatically draw in data from existing sources. The Backpack could intelligently compare data against eligibility criteria, highlighting any appropriate services they may be entitled to access. Information could be verified through the Backpack (e.g. this person is on the MS Scottish Register) to automatically prove eligibility for services (e.g. Blue Badge).

Insight 4

The MS nurse manages a very large case load of patients and does not receive information when there has been a change in their situation (e.g. an admission to hospital) or the outcome of a referral to another service.

Concept 4: Tools for the Specialist MS Nurse

With permission from the Backpack owner, the system would notify the nurse of any changes in their condition or circumstances recorded by the person or their health and care professionals. These patients would be shown at the top of the list to enable the nurse to better manage their caseload prioritising people who may need their support. The nurse would be able to send out emails to all their patients via the Backpack.

Next steps

We hope to share the findings of the project with policy makers in health and care, to highlight the challenges identified and the need for new resources to support information sharing and communication between people and health professionals. We are continuing to work on the Backpack concepts to help to further develop, test and demonstrate the potential benefits of these approaches in supporting person-centred and convenient access to services

For more information

Researchers:

- Gemma Teal, g.teal@gsa.ac.uk
- Dr Tara French, t.french@gsa.ac.uk
- Dr Jay Bradley, j.bradley@gsa.ac.uk

The Innovation School, The Glasgow School of Art, Blairs Farm Steading, Altyre Estate Forres, IV36 2SH

Telephone: 01309 678 146

www.gsa.ac.uk/ExpLabs

8 Research

Results from the MS foot drop study NHS Ayrshire and Arran

[Watch the video on the Foot Drop Study.](#)

We know that people with MS report walking limitations as one of their most significant issues and that foot drop is a common problem. In the UK ankle-foot orthoses (AFO) are considered as usual care in the management of foot drop in neurological conditions despite limited evidence of its effectiveness in MS. There is growing evidence of a positive impact of functional electrical stimulation (FES) on walking, but only one small study has compared these 2 treatments in MS. I am delighted to report that the MS foot drop study, which I highlighted in last years report, is now complete. This study, which recruited 84 people with MS from 7 NHS Boards across Scotland, is the first randomised trial to compare AFO and FES in MS.

Participants were randomised to receive either; AFO, a polypropylene splint which fits into a shoe and keeps the foot up when walking, or FES which electrically activates muscles at the front of the leg to lift the foot up when taking a step. Participants were assessed initially following provision of these 2 devices and then again at 3, 6 and 12 months. We investigated the impact of both devices on the speed and energy cost of walking, falls frequency, fatigue, activity level and a number of quality of life measures. In addition we compared the cost effectiveness of the devices and explored participant’s experiences using the devices and their impact on daily life.

Both devices improved walking speed when walking with their respective devices in comparison to without, however there were no significant differences between the groups with regards to these effects. There were small positive changes in the quality of life measures and on fatigue and these effects were most notable within the first 3 months. There were reductions in the number of fallers (more than one fall) from baseline up to 6 months in both groups from around 23% to 5.5%.

A large number of participants dropped out during the study and this was more noticeable in the AFO (45%) than the FES group (31%). A high proportion of drop outs in the AFO group were related to issues with the device itself. Significantly higher scores in the FES compared to the AFO group in the Psychological Impact of Assistive Devices Scale, which is predictive for device retention and abandonment, suggests that FES may be more acceptable than AFO. Analysis of the participant’s experiences using their device has only been undertaken in the FES group to date. Participants reported improvements in many aspects of walking, increased participation in valued activities and a positive impact on emotions, outlook and mental well-being with FES use.

This study also found that FES was a cost-effective treatment option for foot drop in MS and that cost-effectiveness of FES could be improved if people continued to use their device for longer, offsetting the initial purchasing costs of the equipment.

We hope the results from this study will help guide clinicians to choose the right treatment for people with MS who present with foot drop, thus improving walking, reducing falls and enhancing their quality of life over the longer term.

Linda (Miller) Renfrew
Consultant Physiotherapist in MS
NHS Ayrshire and Arran MS service

	Recruitment Centre				
	Aberdeen	Dundee	Edinburgh	Glasgow	Inverness
Patient Health Board					
A&A			2	10	
Fife		5	5		
Forth Valley			5	7	
GG&C			7	55	
Grampian	20		1		
Highland	1		1		3
Lanarkshire			2	18	
Lothian			94	1	
Orkney			1		
Tayside		28	3		
Western Isles			2	1	
Total	21	33	123	91	3

Anne Rowling Regenerative Neurology Clinic

The Anne Rowling Clinic, opened in January 2013, is at the forefront of patient-centred research into presently untreatable conditions such as progressive MS, MND and the Dementias. Our vision is to give every patient an opportunity to participate in a suite of research studies that collectively will provide new knowledge and lead to clinical trials.

Current MS Research in the Anne Rowling Regenerative Neurology Clinic

Microbiome Study - The International collaborative study with University of California, San Francisco looking at the microbiome in the gut in people with MS and their partners/carers. We are looking to recruit 500 participants from Scotland and recently celebrated its 200th participant. A big thank-you to everyone who has taken part. Recruitment remains open for this exciting single visit observational study.

PHQiMS Study - Low mood and depression is known to affect over half of all people with multiple sclerosis (MS) at some point in their illness. This study will investigate whether a short questionnaire that screens for depressive symptoms works as well as identifying depression in people with MS as it does for people without MS. The study is currently recruiting participants from NHS Lothian.

MS Stat2 - Secondary progressive MS simvastatin trial - This new clinical trial will open to recruitment from the beginning of August 2018. This trial looks to investigate the effectiveness of Simvastatin compared to placebo in secondary progressive MS in slowing the progression of disability. Participation will involve 6 monthly visits to the Anne Rowling Clinic over the course of approximately 3 years.

Rowling CARE (Clinical, Audit, Research and Evaluation) - This national research interest registry development has been driven by people living in Scotland with neurological conditions, including MS, and those caring for them. The purpose is to give information about current and future research to enable people to participate in the appropriate studies or simply to learn about current research activity. Rowling CARE is a Scottish registry and therefore a valuable resource for identifying potential research participants (www.rowling-care.org.uk).

FutureMS - FutureMS is a Scotland wide observational study trying to predict at the point of MS diagnosis the long-term outlook or prognosis for the individual. This is the beginning of personalized

medicine. In time it will give patients more choice and help them and their doctors in knowing when to take (or not) a given treatment.

FutureMS began recruiting in May 2016 and now sees patients in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness. Patients attend a baseline visit which includes an MRI scan, blood collection (for genomic analysis), clinical examinations and a health and lifestyle questionnaire. Patients return after 1 year for a follow up visit incorporating another scan and questionnaire. As of 30th April 2018, 272 people have been recruited and 84 of those have returned for their second visit completing the study. This project is a national effort with people taking part from 11 health boards at present, table1. FutureMS is progressing well, generating a large amount of data each week. The study will finish recruiting patients in 2019 and attentions will turn to analysing and interrogating the data.

All participants have the opportunity to be followed up long term providing a hugely valuable dataset of disease course. Participation in this study will help inform the care and management for those diagnosed with MS in the future. This will enable more informed decision making for both the clinical team and patient.

“It’s just nice to feel like you’re helping, almost a comfort thing. It would be great just to have some idea of what I might expect from my MS.” - Quote from FutureMS participant

9 MS Specialist Nurse

Moira Flett, Specialist MS Nurse, NHS Orkney



I use both genograms and ecomaps, and find that they capture a lot of information succinctly and visually and helps to provide a more comprehensive person-centred service. These tools identify the patients priorities and inform actions for a suitable care plan in partnership with the patient. For example highlighting that a single parent with MS, whose children have additional needs is also currently supporting a family member with palliative care and working part time provides information to collaboratively explore appropriate strategies to manage her fatigue and help us identify and refer to partner support services. This knowledge prevents me from recommending inappropriate and unachievable actions and advice that could lead to feelings of failure and helplessness for the

patient.

This would result in loss of confidence and possibly disengagement with the MS Nursing service.

GENOGRAMS

- Visual and succinct
- Captures family structure, rank order, health problems and risks in members of the family/carer
- Families tend to enjoy speaking about family, and so this helps develop a strong therapeutic relationship and demonstrates interest
- Allows us to tailor our advice and support to the patient and family
- Provides an understanding of dynamics, communication patterns, behaviours
- Allows us to foresee risk of future illnesses
- Allows us the opportunity to discuss family issues
- It helps us understand how the family group influences the individual, and how the behaviour of one in turn influences the group
- Allows the family to see themselves in a more global perspective

ECOMAPS

- Visual and succinct way of capturing family's informal and formal support
- Captures strength of bonds/relationships/support or otherwise between family members, friends and services
- Identifies if they have effective or ineffective support systems
- Initiates discussion e.g relationships, support, values etc
- Allows us to tailor our advice and support to the patient and family
- Provides an understanding of dynamics, communication patterns, behaviours
- Helps us understand how the family group influences the individual, and how the behaviour of one in turn influences the group

10 MS Society

MS Society Helpline

[Watch the MS Helpline video.](#)

MS on your mind? Freephone: 0808 800 8000. Our MS Helpline gives emotional support and information to anyone living with MS. This includes information on symptoms, research, diagnosis, accessing services, support and benefits, and getting in touch with the MS community. We're here Monday to Friday, 9am to 7pm except bank holidays.

It's free to call from landlines and mobiles within the UK. What you tell us is confidential and when you call us, it won't show on your phone bill.

You can send us 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.

Living Well with MS

The MS Society offers the Living Well with MS programme of work which is aimed to support people who have been newly diagnosed with MS. This offer looks at connecting peers both face-to-face and virtually and gives people the opportunity to share their experiences and understand how to live well with MS. Information about the sessions can be found [here](#).

If you are interested in finding out more about how to access a local or virtual Living Well with MS session then please [click here](#) for more details.

Local Networks

We have three Local Network Officers who help and support the volunteers who run 29 Groups across the whole of Scotland. The Groups differ from offering social activities events providing peer support and a network to those whose lives are affected by MS to varying types of exercise to counselling. Our Groups can also provide information and support as well as grants to help pay for items that will have a significant positive impact on the lives of those affected by MS.

If you are interested in finding out more about a local group in your area then please [click here](#).

Active Together

Our Active Together project was co-produced with volunteers from the MS community to increase physical activity levels for people with MS. Through working with local and national partnerships MS specific activities were offered such as curling, circus skills, archery, horse riding, walking and rambling for people to try. We also worked with our local volunteer MS groups to provide MS specific physical activity services and develop the volunteers to increase their confidence and awareness of people being physically active.

UK wide the MS Society has developed a range of exercise videos to help people remain active. These include adaptations so that people with a range of disabilities can take part. You can find more about the Active Together programme on our [website](#).

[Watch the Active Together video.](#)

11 MS Revive

[Watch the MS Revive Support video.](#)

Our clients continue to be the focus of all our services and activities. We continue striving to empower those affected by MS by providing information, support, therapies, and advice about the condition from time of diagnosis and throughout the disease spectrum and to accompany them on their individual guided journey.

Within the last year our new client base has grown by an unprecedented 40% with 226 people registering to use our services. More and more clients are accessing our services with a total of 24,440 individual interventions being delivered, representing an increase of 23%.

Alongside the established clinical services we provide, Revive successfully piloted three new projects. These included:

- **Making Sense of MS** – a new four-week programme (in partnership with QEUH & Chronic Disease Management Team) to help those affected by MS come to terms with their condition. We identified 28 separate areas of unmet need amongst those recently diagnosed, reflecting the life-changing impact of the disease. Covering all aspects, the programme aims to: Increase understanding of MS at a time of great anxiety for those affected; encourage self-management, preparing participants for the day-to-day challenges of MS (ranging from fatigue to depression and other common symptoms), and how to manage these pro-actively; signpost participants to the best treatment and services relative to their specific type of MS, increasing their choices and control in relation to their condition.
- **Digesting Science** – focused on the critical role of families in the support and care of relatives affected by MS. By explaining, illustrating and practically demonstrating the precise nature of MS from the patient's perspective, the programme is aimed at primary school children and enables them to gain the clearest possible understanding of what their parents are experiencing, day-to-day, both mentally and physically.
- **Access Revive MS Services (ARMSS)** – this directly addresses the needs of the significant proportion of people diagnosed with MS who have no, or very limited, access to services and support, in part due to their location, but also due to the severe mobility restrictions that affect over 50% of people with the condition. Using Attend Anywhere the service offers support by video consultation to people with MS in their own homes. It includes appointments with an MS Nurse Specialist, continence advice and support, speech and language therapy, and more.

Amongst the new initiatives introduced by our Physiotherapy Team is a new MS Walking Clinic. The Clinic is delivered by Revive's Senior Physiotherapist with support from an external Orthotics specialist and the Lead Physiotherapist from the Queen Elizabeth University Hospital. The Clinic provides MS clients with appropriate information on how their MS is impacting on the way they are walking (gait pattern) and helps them (and their carers) to understand what they can do to address any issues they have. Clients receive a detailed assessment from the physiotherapist and orthotist which includes the client's own perceptions of the impact of MS on their walking and physical tests to review their gait pattern with video analysis. Clients discuss the range of options available to them to help them manage their mobility and receive on-going support through the clinic as required.

The ability to innovate, along with our long history of providing services for people affected by MS demonstrates our expertise and trusted model of service delivery which is recognised by our many partners.

12 MS Mid Argyll



The MS Centre Mid Argyll has been supporting people affected by MS since 1996 living in the Argyll area. The MS Centre was purpose built for this use and has a hyperbaric chamber in it, the building was designed around this.

The MS Centre has a range of activities on daily such as oxygen therapy, massage therapy, Zumba Gold, Stretch and Tone, Arts and crafts, Singing for Fun just to name a few.

In 2013 the service expanded when the MS centre managed to secure funding for an outreach worker this was for three years initially and in 2016 they managed to extend the funding to keep this valuable outreach service running.

Claire the outreach worker covers Mid Argyll, Kintyre, Islay and Jura delivering home support, group work and training for those affected by MS. Claire supports not only the person with MS but also their family, friends and work colleagues.

The service has grown over the years since it started up as it is the only service of its kind in this area. People living in rural isolation do not have the same resources, support and ability to communicate with the people they need the support from.

Some people who have been diagnosed with MS go back to living in a rural community with very little or no support to help them understand their MS or the affects that it has on daily life, this can be very demeaning to them and also the people around them.

A big part of Claire's role is raising awareness of MS, Claire attends many local events, trains companies, school and community groups on the symptoms of MS and the affects that it can have on people's lives.

Claire also signposts to other organisations and health professionals which Claire and the MS centre work very closely with to help make sure people are getting the best support they can locally. She also takes small groups of people out for peer support and to socialize but most of all just for a good old chat.

13 Events and Awards

Barts

Barts-MS and Glasgow neurology team, recently teamed up with the Western Isles MS Nurse to host two research days on the islands. The event took place over two days, one day of talks for the healthcare professionals, a second for people affected by MS and a Digesting Science event for the children who attended.

Attending the first day were district nurses, GPs, physios, health visitors and others who care for people with MS in a professional capacity. We wanted to give these professionals more of an insight into specialist care for people with MS, and talks included information on holistic care, self-management and technology in care.

The second day was for families. People with MS attended with their loved ones and heard about the latest research into nutrition and exercise, Vitamin D, available treatments and the future of MS care. The talks were all filmed and are available on the [Barts-MS Youtube channel](#).

Digesting Science

Digesting Science is an award-winning set of educational activities aimed at teaching families about the science and impact of MS through a fun and creative approach. Digesting Science events are run over half a day where families can come together and undertake the activities with the assistance of a facilitator or volunteer. This event can offer the healthcare professional an opportunity to meet the family though the activities are designed and kits are available to anyone who would like to run an event. Find out more about facilitating an event at: <http://www.digestingscience.co.uk/>

Rachel Morrison

Rachel Morrison, MS specialist nurse in NHS Western Isles was awarded the QuDoS in MS award. The programme recognises innovation and excellence in care and service delivery in Multiple Sclerosis.

“Rachel is passionate about her work, using technology to video conference patients from their own homes.”

Rachel has been instrumental in supporting people with MS living in the Western Isles, providing a comprehensive service from initial contact through to diagnostic process and longer-term care for patients and their families. She tailors her care to address the needs of those with MS using personal visits and technology, where practicable. She enables patients to contact rehabilitation consultants via videoconference in their own homes, negating the need for them to fly to Glasgow.

Rachel is committed to delivering excellence to her patients and is extremely knowledgeable about the range of medications available for them as well as potential side effects.

Rachel is involved in planning and organising a range of training opportunities for staff and patients alike. She has trained home carers and student nurses in how best to support complex MS cases and gives talks on MS to local groups. She organises information events throughout the Western Isles aimed at raising awareness of MS. She has led on the implementation of a localised service for both

Tysabri and JCV testing, enabling patients to be managed closer to their own homes without leaving the islands.

She goes above and beyond in her determination to provide her patients with the best care possible.

This was taken from Qudos In MS

14 From Your Boards...

All health boards were contacted with a request to comment on their data in relation to the local MS service provision.

NHS Ayrshire and Arran

NHS Ayrshire & Arran has a population of 366,800 and 1064 people with a confirmed diagnosis of MS managed by the MS Team at the Douglas Grant Rehabilitation Centre. In 2017 there were 44 patients diagnosed with MS. Of the active caseload 34% are currently in receipt of a disease modifying therapy. The MS service is multidisciplinary with MS Specialist Nursing, Allied Health Professionals and other services. The MS Service sits within the Neurological Rehabilitation Service and the non medical Clinical Lead for Neurological Rehabilitation continues to support future service development.

Medical input is delivered through a joint Consultant MS Neurologist appointment with NHS GG&C 0.4 WTE per week delivered within NHS Ayrshire and Arran. MS specific clinics are held weekly within the centre and/or at peripheral clinics in community hospitals at Girvan and Cumnock. 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 MDT. Two members of our MS MDT are non-medical prescribers and support with symptom management.

People transitioning with MS and who require medical review are seen by a fixed term Consultant in Rehabilitation Medicine (0.4 WTE) or the Specialty Doctor in Rehabilitation Medicine (0.4 WTE) (joint post with NHS GG&C). There continues to be national challenges appointing to Rehabilitation Medicine Consultant vacancies and work continues with other Health Board areas to address this issue. The Douglas Grant Rehabilitation Centre continues to offer a one-point of contact and patients are encouraged to self-refer at any time through supported self management programmes.

The Service continues to meet MS specific national standards with the exception of MS Nurse contact being made within 10 working days of diagnosis. We continue to look at how we can further improve on this. Contact with the MS Nurse within 10 working days of receipt of referral continues to achieve 100%. Patients who are diagnosed with clinically isolated syndrome (CIS) have full access to the MS MDT service and are kept under routine review.

We continue to offer a range of educational events for people diagnosed with MS, such as Getting to Grips with MS, and general awareness sessions run jointly with the MS Society Ayrshire and Arran Groups. Bi-annual study days are offered for professional staff and health and social care support workers from secondary, primary and community care settings.

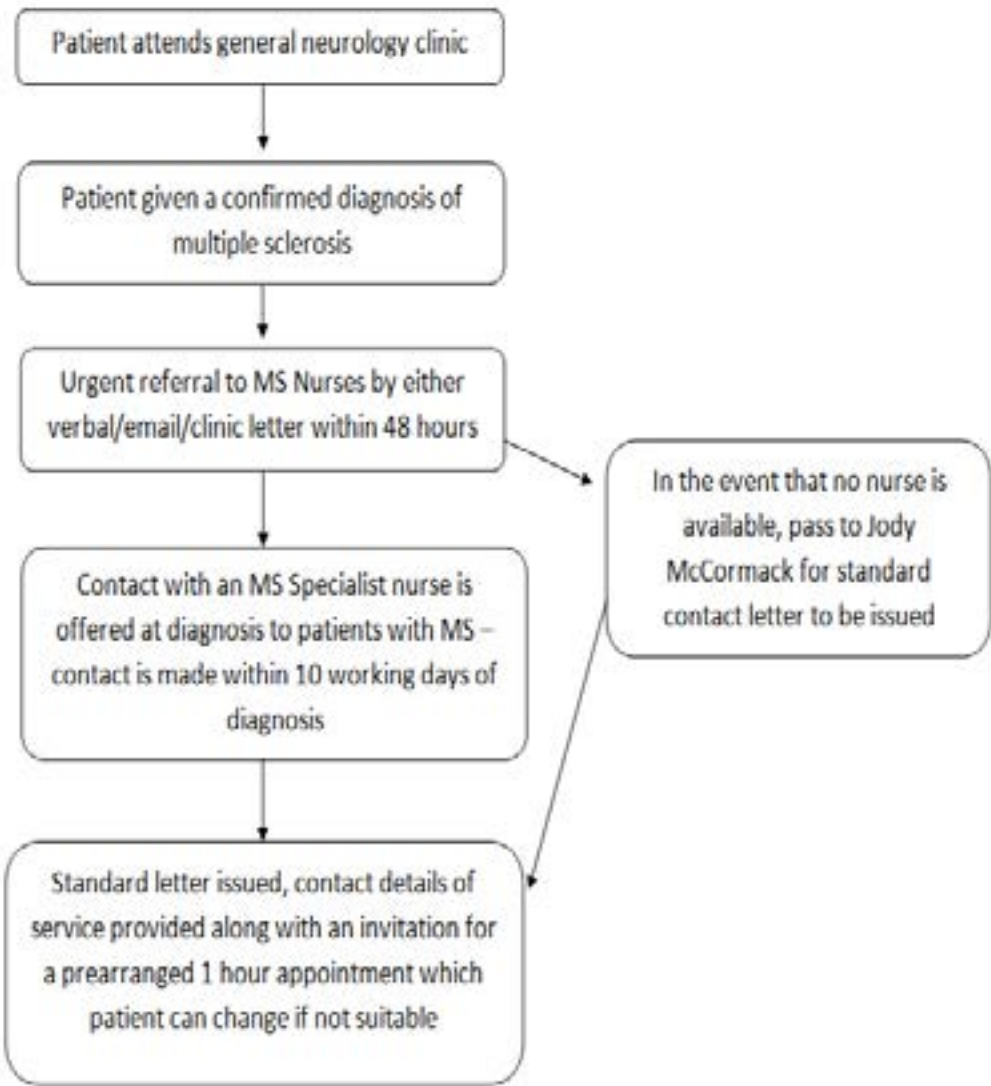
Due to workforce issues and staff retirements we have had to access a range of options to continue supporting the service. Further redesign work is also underway to improve the patient experience and to enhance our efficiency. NHS Ayrshire and Arran MS Service is committed to continuing to improve services to those affected by MS.

NHS Borders

In 2017 NHS Borders continued to record the lowest rate in Scotland in respect of the incidence of MS per 100,000 of the population and has not experienced any significant variation in the annual number of newly diagnosed cases since 2010 (7 new cases each year from 2011 to 2015, 6 new cases in 2016 and 7 in 2017). 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. In practice

MS Service Flow Chart for newly diagnosed patients (as per Scottish MS Register Standard 15.2)



referral takes place on day of diagnosis. All National Report 2018/Scottish Multiple Sclerosis Register patients in 2018 were contacted by the MS Nurse within 10 working days.

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. A stakeholders meeting took place in May 2018. There was representation from the MS Society. At this meeting, service providers considered with stakeholders how resources are used to deliver services, staffing and performance issues and feedback was sought using the "Health and Social Care Standards – My support, my life" framework.

NHS Forth Valley

MS Service Flow Chart for newly diagnosed patients (as per Scottish MS Register Standard 15.2)

NHS Lanarkshire

The MS service in Lanarkshire experienced a very challenging time during 2017 due to the resignation of the MS Specialist Nurse, however arrangements were put in place to support patients whilst a recruitment campaign was undertaken to replace the post.

The MS Trust worked with NHS Lanarkshire to fill the vacancy, as well as funding a specialist nurse, and supporting the recruitment of a Neurology Specialist Nurse, to provide care to both people with MS and Parkinson's. These staff were appointed in October 2017. Dedicated support was also provided by a Specialist Consultant Neurologist and management team.

These specialist nurses continue to receiving on-going support and mentorship from the MS Trust Specialist Nurse Programme team, as well as funding to attend the MS Trust's foundation training course for new-in-post MS specialists and the charity's annual conference for MS health professionals.

NHSL have put a number of support measures in place including admin, phlebotomy and digital solutions to allow these nurses the opportunity to increase their capacity to see patients timeously following a clinical diagnosis of MS. In addition we have received a highly positive patient survey as well as improved access to services. We anticipate that in 2018 we will see a significant improvement in our overall performance as we continue to grow this person centred specialist MS service.

NHS Lothian

NHS Lothian is pleased to note that its MS team has improved the percentage of newly diagnosed MS patients, who are seen by a MS Nurse within 10 working days, by around 10% to 80%. This is a tribute to the team who see a comparatively high numbers of patients per member of staff.

The delay in the remaining patients being seen within this timeline lies before referral to the MS Nurses, once the referral reaches the Nurses, 100% of patients are seen within this time. This is an improvement of 4.6% from last year.

One of the areas of improvement that the team are focussing on is referral pathways, examining the number of routes of referral to service, streamlining processes with an aim to increase speed of access.

NHS Western Isles

The Neurological Managed Clinical Network (NMCN) takes responsibility for service developments for Neurology Services, with regular reports directly to the Long Term Conditions Steering Group on progress. The implementation of the Neurological Strategy and action plan is being led by Public Health Planning and Development team.

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 Greater Glasgow and Clyde (consultant neurologists), to ensure expert medical management is delivered to MS patients living across NHS Western Isles.

We have a MDT for all neurological conditions including MS constituting of local rehabilitation services (Speech and Language Therapy, Dietetics, Podiatry, 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 consultants; patients Attend Anywhere in from Southern Isles and to link in with mainland services.

Recent Improvements/Initiatives

1. Tysabri and Lemtrada service is now offered island wide – with staff targeted in training in this service to increase service awareness and capacity;
2. Florence – web based clinical interface that collects data from patients via their mobile phone – monitoring pelvic floor, sleep studies (with fitbit), medication compliance, exercise tracking and weight and relapse monitoring.
3. Morse – a fully integrated mobile platform to bring primary, secondary and eventually social care together in a single mobile app which downloads patient data from central systems – evidenced across various services to reduce admin time by 40%.
4. 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;
5. Attend Anywhere conferencing links to rehab consultants on mainland now offered as a substantive service.
6. Exploration of VC clinic use – rapid access clinic, virtual outpatient clinic
7. BEAM – telepresence robot – utilised with a young family to reduce risk and stress and supporting partner/carer to be able to maintain daily routine i.e. work, school etc
8. Rehab consultant now visiting 3 times yearly for MS and spasticity (botox)
9. MS Roadshow – 2 day event with Prof Chandran – encompassed sessions for GP and Clinical Staff (Students, Social Work, Midwives and third sector) and a patient session; BARTS – 1 day clinical session with a session running in conjunction for “digesting science” – support for families;
10. 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;
11. MCN currently exploring options for service and pathway redesign which will look to establish pathway leadership and pathway monitoring and performance management. This will be supported a shared and integrated infrastructure (technology and systems).

15 Acknowledgements



The SMSR central team from L to R – Gillian Gillespie, Martin Paton, Chrissie Watters.

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.

This annual National Report was prepared by Dr Niall MacDougall, Dr Pushkar Shah, Dr Elizabeth Visser, Linda Renfrew, Martin Paton, Martin O'Neill, Dr Jonathan O'Riordan and Chrissie Watters with contributions from , Rachel Morrison, Mhairi Coutts, Moira Flett, MS Society, MS Revive, Mid Argyll Centre, Glasgow School of Art.

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