Lanarkshire MS Nurse Service

MS Trust Specialist Nurse Programme Final Report

August, 2019

Christine Paterson, Claire Millar, Claire Purdie, Julie Wilkie, MS Specialist Nursing Team, Lanarkshire

Guy Hannan, Evaluation Manager MS Trust

Sponsored by the MS Trust





Introduction to this report

Lanarkshire MS nurse service is a pioneering member of the MS Trust's MS Specialist Nurse Programme. The programme contributed 18 months' funding towards a new MS nurse post together with mentoring and wider support for quality improvement to enable the service to quickly realise the benefits of the new resource.

This report summarises the activities, achievements, and learning from the programme period, Sept 2017 – March 2019 and describes the impact on people with MS's experience of care.

In this report:

- Components of the Specialist Nurse Programme
- Achievements of the Specialist Nurse Programme
 - Activity
 - Patient experience
 - Impact on patient outcomes

Summary of findings

Evaluation was conducted to understand differences made from the start to the end of the programme (18 months). This included a focus on:

- MS nurse activity and patients seen
- Patient experience
- Patient outcomes

• The MS Specialist Nursing Team have increased their activity and now see a lot more people with MS:

- 17 new DMD phlebotomist clinics a month means MS nurse time has been freed , meaning routine appointments increased from 15 to 30 minutes allowing time for holistic reviews
- MS nurses now conduct joint visits with social workers, home visits have increased, and there are new relapse appointments and newly diagnosed clinics (with 93% of those newly diagnosed offered an appointment within six weeks, compared to 76% before the programme)
- The average number of phone consultations per person per year increased from 0.33 in 2018 to 2.58 in 2019, due to improved provision of phone support
- Improved communication with other health professional s, e.g. GP information packs now sent when patients newly diagnosed. Now get more referrals and telephone enquiries from GPs, improving coordination of care
- Compared to a year ago, many more people saw an MS nurse (79% compared to 55%) and were offered an annual review (51% compared to 32%)

Patients are getting better experience/care

- 75% felt the service gave trust and confidence in their expertise, compared to 58% a year ago
- 64% felt involved in decisions about their care, compared to 49% a year ago
- 92% found advice on accessing other health professionals helpful, compared to 78% a year ago

Better patient outcomes and financial savings

- 45%, compared to 35% a year ago, reported MS nurse contact resulted in at least one positive wellbeing impact (which is in line with other services who have gone through the programme)
- 11%, compared to 13% a year ago, reported being admitted to hospital about their MS in the past year, with an average stay of 6.5 nights compared to 9 nights (which is the biggest decrease in programme sites)
- Based on the reduction in numbers of people being admitted to hospital, it is estimated that approximately £45,929 have been saved compared to a year ago
- Approximately £74,500 in ambulatory cost savings have been made, based on other healthcare services patients said they would have used (e.g. GP and A&E visits) had the MS nursing service not been there

Components of the specialist nurse programme

Milestones during the Lanarkshire Specialist Nurse Programme

Expression of Interest shortlisted by the MS Trust (Summer 2016)

Full bid successful.
Lanarkshire becomes 1
of 3 pilots for the MS
Trust Specialist Nurse
Programme (Autumn
2016)

Business case for two new band 6 MS nurses successful (one to be funded through the MS Trust Specialist Nurse Programme) (April 2017)

Collaboration agreement signed between MS Trust and NHS Lanarkshire (May 2017) Advertisement, shortlisting of applicants for the new roles leading to the appointment of three new MS nurses (July 2017)

MS Trust HPP Manager provided 3 monthly mentoring to the team throughout the funding period. (Commenced Dec 2017)



MSSNs attend MS Trust Conference (Nov 2017)



1st Stakeholder Meeting to discuss and agree KPIs for the MSSN service held (Oct 2017)



Claire Millar, Claire Purdie and Julie Wilkie, new MS specialist nurses come into post (Sept/Oct 2017)

MSSNs attend the MS Trust 5 day, residential Development Module (March and Sept 2018)



Off-site evaluation, training and service development meeting (October 2018)



Collation of data and information for the final report (March 2019)



3rd steering group meeting and stakeholder event to celebrate their achievements during the programme (September 2019)

Professional Development for new MS nurses

Participation in the Specialist Nurse Programme brought funded opportunities for knowledge and skills development from the MS Trust and a focus on sharing and mentorship between new and more experienced members of the team.

Professional development

- ✓ MS Trust Development Module a five day course providing foundation knowledge in MS and skills to manage clinical and professional issues relevant to the specialist role (20 credits awarded by Birmingham City University)
- ✓ MS Trust Conference (2017)
- Mentoring from the MS Trust's Health Professional Programmes Manager, approx every three months, commenced Dec 2017
- Team supervision during weekly team meetings and with the Consultant Neurologist to enable effective case management and sharing of good practice.

After taking part in the programme and attending the MS Trust Development Module I feel less like an imposter of an MS nurse.

Claire Millar, MS Specialist Nurse, NHS Lanarkshire.

Rewarding, challenging, inspiring, patient-centred, constantly learning.

Claire Purdie, Neurology Nurse Specialist, NHS Lanarkshire.

I would like to say how very thankful I am that the MS
Trust has been involved in supporting our service over the
last 18 + months. The learning, support and
encouragement we have received from the MS Trust has
led us to where we are today and gave us good grounding
to continue developing an excellent service for our
patients.

I truly feel empowered through continued education sessions with Megan and through the MS Nurse Development Module education and support, and in so, empowering our patients/ service users every working day. On reflecting on our latest report I am overwhelmed by how well our wee team and service are doing and I think its important to acknowledge the MS Trust in this regard. I feel that I am a confident practitioner within my field of specialty and a great deal of that is due to the support that MS Trust have invested in our service.

Julie Wilkie, MS Specialist Nurse, NHS Lanarkshire.

Stakeholder Group

The MS nurse service established a 'task and finish' stakeholder group to update colleagues on progress during the Specialist Nurse Programme and discuss service improvement. The group has met twice (Oct-17 and Feb 2019) with a final meeting planned for September 2019.

Aims of the stakeholder group

- To review the MS nurse service's baseline data
- To review MS nurse service level data, key performance indicators and overall progress
- To support service development within the MS nurse service
- To explore how data and learning from the MS Specialist Nurse Programme can inform service development across the MS service
- To identify and work jointly on service improvements to deliver patient centred care across the MS service

Membership of the stakeholder group

- MS nurse team Claire Millar, Claire Purdie and Julie Wilkie
- Dr Niall MacDougall, Consultant Neurologist, MS
- Christine Paterson Team Leader, Long Term Conditions Lead
- Karen Maclure Service Manager
- Christine Robertson, Senior Information Analyst

I felt that there was a real need for a strong MS nurse team to help support the large number of people with MS in our area. I was very interested in the whole process and I found the engagement from the MS Trust and the local management team to have been very useful in appointing the new nurses. Beyond that the support from the MS trust in education, mentoring and development of the team has been excellent.

Niall MacDougall

The stakeholder group was invaluable as it facilitated shared learning and allowed the stakeholders to check in on the team's progress. Furthermore it enabled collaborative decision making on future service development.

Christine Paterson

A very positive working relationship with MS colleagues transforming MS services for our patients in NHS Lanarkshire

Karen Maclure

Off-site evaluation training and service planning workshop

In October 2018 the entire MS nurse team of three MS nurses and their team leader took part in a 1.5 day residential workshop that covered the theory and practice of evaluation and gave the team the opportunity to plan and work on quality improvement. The session provided the time and space for the team to focus on the following outputs:

- Review improvements that had been made to managing incoming / outbound calls
- Develop and agree patient information on relapse and use of steroids.
- Develop and agree an Information pack for people newly diagnosed with MS
- Extend MSSN clinic appointments from 15 to 30 minutes through more effective use of Phlebotomy service enabling the MSSNs to use their specialist skills on providing assessment and advice to pwMS more effectively.

Quality Improvement Goals - The MS nurse team set quality improvement goals to be met by October 2018
☐ Reduce number of MSSN appointments used primarily for taking blood
☐ Address the lack of availability from social services
☐ Increase numbers of home visits
☐ Improve provision of relapse service
☐ Discussed implementation of service improvements based on baseline results of MS Trust patient survey
☐ Offer an appointment to everyone newly diagnosed with MS so they can be seen within six weeks of receipt of referral
☐ Improve provision of phone support

Achievements of the Specialist Nurse Programme (summary)

Summary of achievements

Progress against improvement goals

Improvement Goals set	Progress against these
☐ Reduce number of MSSN appointments used primarily for taking blood	✓ There are now 17 new DMD phlebotomist clinics running each month with a clinical support worker taking blood. This has freed up MSSN time to provide longer review appointments
☐ Improve on the lack of availability from social services	✓ MSSNs now conduct joint visits with social workers and attend case conferences as required. This brings specialist MS expertise to the care of vulnerable adults
☐ Increase numbers of home visits	√ 63% increase in home visits between April to August 2018, and October 2018 to February 2019 (73 and 119 home visits in these periods)
☐ Improve provision of relapse service	✓ There are now four relapse appointments available per month, one per week. There were previously no specific appointments available for relapse
☐ Discussed implementation of service improvements based on baseline results of MS Trust patient survey	✓ This was repeated in January 2019, with improvements seen across a range of measures (as will be detailed in this report)
☐ Offer an appointment to everyone newly diagnosed with MS so they can be seen within 6 weeks of receipt of referral	✓ There are now four newly diagnosed clinics a month, with 93% of those newly diagnosed being seen within six weeks from October 2018 to May 2019, compared with 76% from March to September 2018
☐ Improve provision of phone support	✓ Previously patients could call the service two days a week within a two hour window, with no facility to leave a message. Phone line now available during working hours with message facility. Call volume increased (from 170 in January 2018 to 182 in January 2019), and the patient survey indicated average number of phone consultations per person per year increased from 0.33 in 2018 to 2.58 in 2019.

Summary of achievements

Patient survey findings:

- More people seen more regularly
- Improved patient experience
- Greater impact on patient outcomes

	Before the Specialist Nurse Programme	Following the Specialist Nurse Programme
	55% of respondents had seen an MS nurse in the last 12 months.	↑ 79% of respondents had seen an MS nurse in the last 12 months
Activity	32% had been offered an annual review with an MS specialist nurse in the last 12 months	† 51% had been offered an annual review with an MS specialist nurse in the last 12 months
	An average of 1.4 consultations with MS specialist nurse in the last 12 months	↑ An average of 2.0 consultations with MS specialist nurse in the last 12 months
	58% felt the service gave trust them and confidence in expertise	↑ 75% felt the service gave trust and confidence in expertise
Experience	49% felt involved in decisions about their care	† 64% felt involved in decisions about their care
	78% found advice on accessing other health professionals helpful	† 92% found advice on accessing other health professionals helpful
	35% MS nurse service contact resulted in at least one positive wellbeing impact	† 45% MS nurse service contact resulted in at least one positive wellbeing impact
Impact	13% admitted to hospital about their MS in the past year	11% admitted to hospital about their MS in the past year
	9 nights average time spent in hospital per admission	6.5 nights average time spent in hospital per admission

Achievements of the Specialist Nurse Programme (clinical activity and more people seen more regularly)

New clinics and processes have led to better provision of services for patients

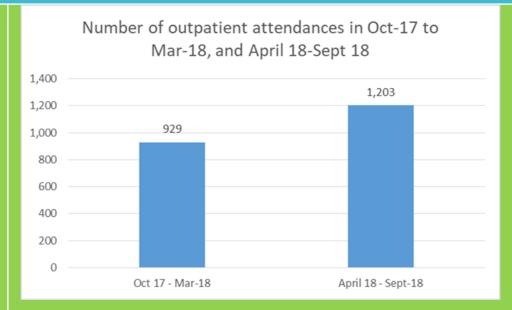
Changes in clinical provision and processes

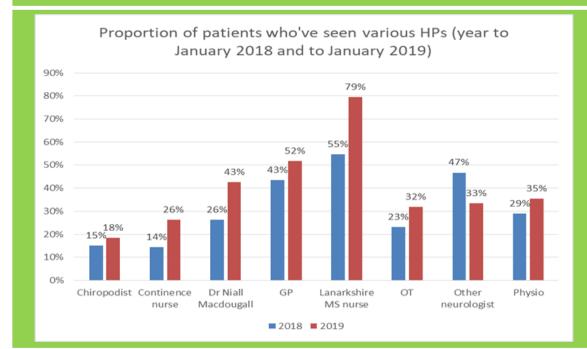
During the first few months following the recruitment of the new nurses, considerable work took place which allowed the service to progress. New standards, protocols, recording systems, and clinics were developed. The new nurses also undertook training, and learning and development at the start of the posts.

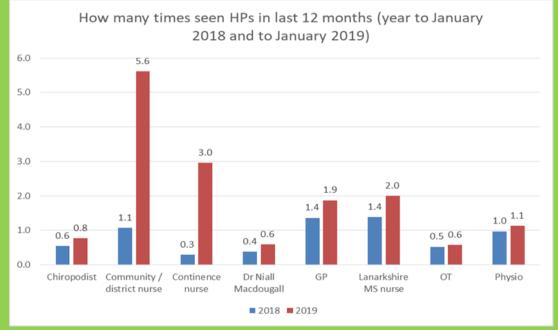
	Before the Specialist Nurse Programme	Following the Specialist Nurse Programme		
	No phlebotomy support meaning considerable MS nurse time was spent taking blood samples	MS nurses now provide 30 minute review slots due to time saved by the 17 DMD phlebotomy clinics a month		
	No newly diagnosed clinics prior to the new nurses starting	Four newly diagnosed clinics a month, one a week at the Hunter Health Clinic		
e	No relapse clinics prior to the new nurses starting	Four relapse appointments available per month, one per week at the newly diagnosed clinic		
	Lack of access to technology to facilitate remote clinics	'Attend Anywhere', a web-based platform allowing virtual clinics so people can be seen closer to their homes		
	Home visits rarely undertaken	185 conducted between May 2018 and February 2019		
	Phone line only available two days a week within a two hour window, and no message facility	Available all working hours with message facility. Also a dedicated email address. These promoted via patient info leaflet and team give out business cards with contact details		
	Inadequate screening forms with no previous structure or standardisation	Four new screening forms developed, including for newly diagnosed and DMD patients, allowing more efficient noting of changes and continuity of care		
	Lack of joined up communication with other health care professionals	GP information pack sent when patients newly diagnosed. Now getting more referrals and telephone enquiries from GPs, improving coordination of care		
	No relapse or steroid pathways	Written by team, Dr MacDougall and pharmacists. One each for GPs		

These new clinics and processes mean more people are being seen, by the MS nurses and other HPs, and that those that are seen are having more contact / are seen more often

- There was a 29% increase in the number of outpatient attendances from the six month period Oct 2017 to March 2018, compared to the six month period April 2018 to Sept 2018 (929 and 1,203 outpatient attendances)
- There were large increases in the patient survey of proportions of people who'd seen various types of health professionals, with those seeing an MS nurse increasing by 24% (55% to 79%)
- There was also a 9% increase in people seeing their GP(43% to 52%). The extra resource has allowed the MS nurse service to develop better links with local GPs, and the relapse and steroid pathways supplied to GPs improves prescribing
- Those that saw MS nurses, and other health professionals, also saw them more often, with the average number of times patients' saw an MS nurse increasing from 1.4 to 2.0
- There was considerable increase in the average number of times patients saw district or community nurses, from 1.1 to 5.6. Although the proportion of patients seeing these was low (at 11%, increased from 8% in 2017/18), the rise in contacts is important because many of these are people with progressive MS.

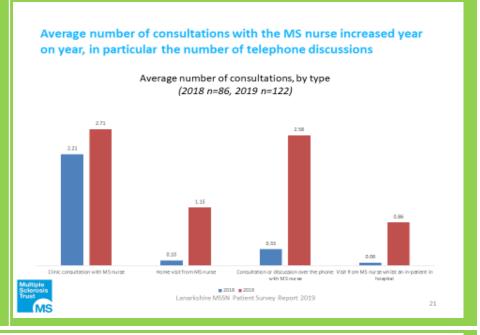


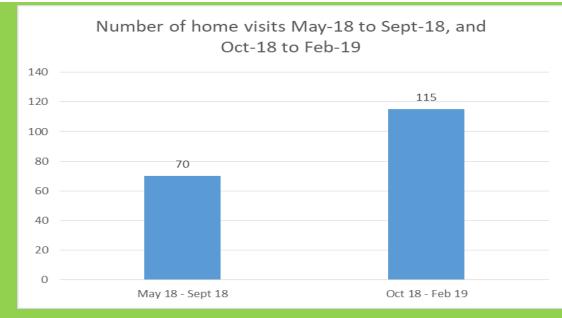


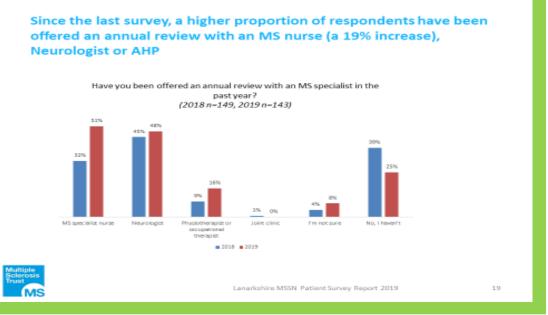


There were increases in numbers of contacts with nurses in each type of setting (e.g. by telephone), and numbers of home visits and annual reviews also increased

- Numbers of consultations with MS nurses in different settings (phone, face to face etc) all increased, with the average number of phone consultations increasing from 0.33 to 2.58. Provision of phone services was significantly increased during 2018, with the phone line being open much more frequently and a message service added
- The average number of home visits greatly increased for those receiving them, from 0.10 to 1.15. Data collected by the MS nurses corroborates this, showing there were 70 home visits between May 2018 and September 2018, and 115 between October 2018 and February 2019 (a 64% increase across these five month periods)
- Many of those visited at home are patients with progressive MS, who are more at risk of hospital admissions, and this, along with the more frequent contacts with district nurses and the fact the MS nurses are conducting more ward visits, may have contributed to fewer hospital admissions (as evidenced on slide 22)
- The proportion of patient survey respondents receiving an annual review with an MS nurse increased by 19% (from 32% to 51%). MS nurse appointments increased from 15 to 30 minutes allowing more time for holistic reviews. As subsequent slides will show, there have been large improvements in various measures of patient experience and outcomes, and longer consultation times could be a key factor







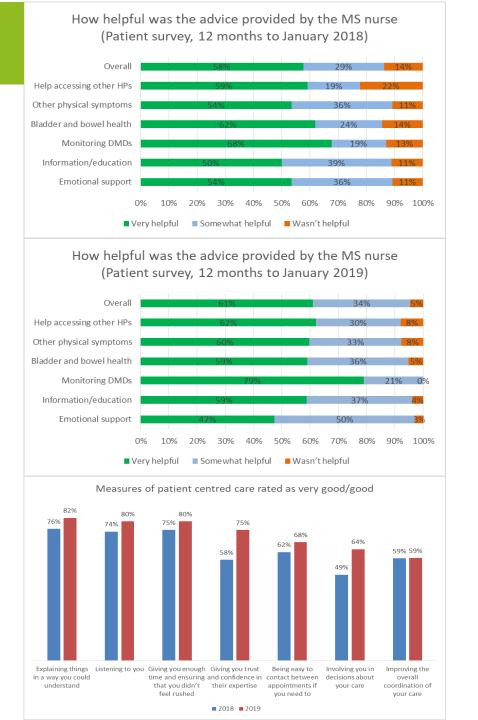
Achievements of the Specialist Nurse Programme (improvements in patient experience)

The changes detailed on previous slides have fed into reported improvements on measures of satisfaction in the patient survey. This demonstrates that the MS nursing team are more effectively addressing patient need

- Nurse advice was more helpful in the 12 months up to January 2019 compared to the 12 months up to January 2018, with only 5% reporting that advice was unhelpful across various measures, compared to 14% in 2018.
- 92% found advice on accessing other health professionals very or somewhat helpful in 2019, compared to 78% in 2018. The nursing team proactively developed communications with other health professionals, with the previously cited increases in patient contact further demonstrating success of this.
- In 2019 79% found advice on monitoring DMDs to be very helpful, compared to 68% in 2018.
- There were also increases in nearly all measures of patient centred care. There was a 17% increase in responses of very good or good for giving trust and confidence in expertise.
 Being involved in decisions about care increased by 15%.
- Various changes, outlined in previous slides, such as MS nurse appointments increasing from 15 to 30 minutes and the service being more easily contactable by telephone, may have contributed to these positive results.
- These results are encouraging in themselves and demonstrate the positive changes the service has made to patient experience. Additionally, they are likely to contribute to improved outcomes for patients, as will be detailed on subsequent slides.

"I am so glad the MS nurses exist. The MS nurses are a lifeline to many of us. I can't praise these wonderful people enough."

Respondent to the 2019 patient survey

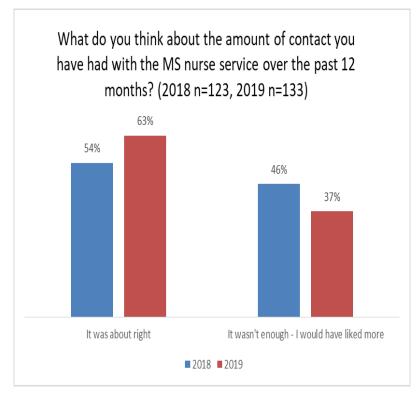


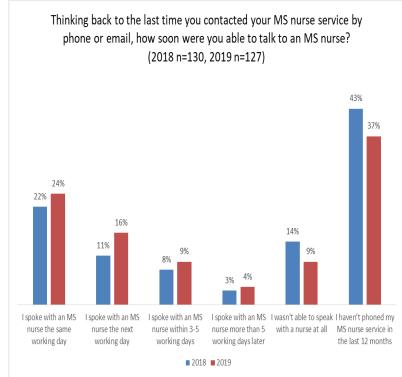
More people were happy with the amount of contact they had, were able to speak to MS nurses quicker and knew when their next appointment was going to be

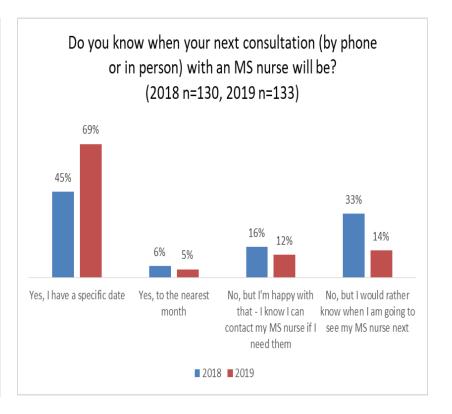
- The proportion of people saying they wanted to have more contact decreased by 9% (from 46% in 2018 to 37% in 2019), indicating that demand for contact is being better met.
- In 2019 more people said they were able to speak to a nurse the same or next day, and fewer people were unable to speak to a nurse at all.
- Overall, more people phoned the service in 2019, 63% compared to 57% in 2018. The MS nurse team contact details were more
 heavily promoted in 2019, through patient information leaflets and business cards, which may have contributed to more contact.
- The proportion of people who knew when their next appointment was rose by 24%, from 45% in 2018 to 69% in 2019. This may have contributed to positive increases in confidence and trust on the previous slide.

"Provides comfort knowing they are at the end of a phone and will always return your call as soon as they can"

Respondent to the 2019 patient survey



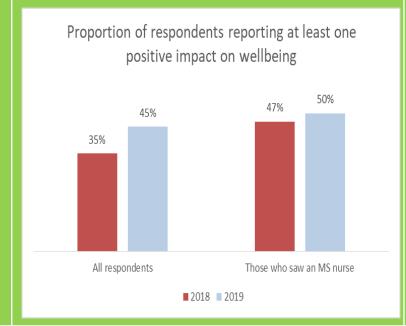




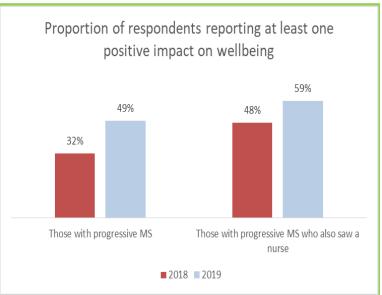
Achievements of the Specialist Nurse Programme (impact on patient outcomes)

Impacts on patient outcomes (1): There were increases in proportions of patients reporting at least one positive impact on their wellbeing. This was particularly the case for people with progressive MS

- Respondents to the patient survey were asked what impact the MS nurse service had on the following aspects of their wellbeing:
 - Overall quality of life
 - Physical wellbeing
 - Confidence I have in my ability to cope
 - Ability to take care of myself
 - Emotional wellbeing
- There was a 10% increase in the proportion reporting at least one of these (from 35% to 45%)
- There was a smaller rise for those who had seen an MS nurse, from 47% to 50%



- There was a 17% increase in proportions of people with progressive MS reporting a positive impact on their wellbeing
- There was an 11% increase for people with progressive MS who also saw an MS nurse
- The substantial increases in home visits conducted by the MS team may be an important factor here, as the majority of those are to patients with progressive MS. Improved referral pathways set up and coordinated by the team are another likely contributing factor



"The MS nurse team has helped me greatly. Their knowledge and understanding of this condition is greatly appreciated, quote "we are all different." I no longer feel isolated, I am listened to, I am no longer on my own"

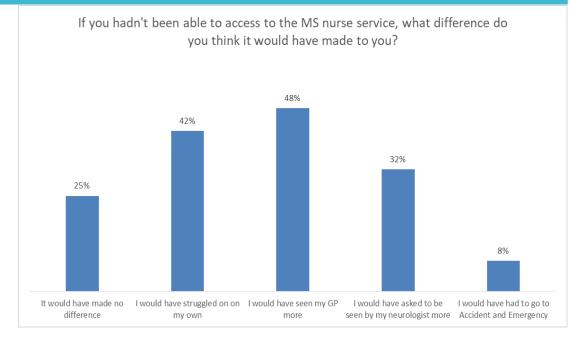
"Informative discussions about wellbeing and positive replies to questions about expected MS progression. Ongoing monitoring by arranged appointments and availability of advice from the nurses by phone if required. The availability of information delivered in a friendly understandable manner is key to keeping a positive outlook towards the future."

"After living with MS for a number of years its comforting to know there are people out there who care and know the effects this can have on your life. I am so glad the MS nurses exist, The MS nurses are a lifeline to many of us, can't praise these wonderful people enough."

Impacts on patient outcomes (2): Access to the MS nurse service has meant that £74,539 cost to the wider health service has been saved in ambulatory costs alone

- Respondents to the patient survey were asked what they would have done had they not been able to access the MS nurse service in the last 12 months.
- Overall, 75% said they would have relied on other health professionals more, compared to 68% in 2018. This indicates that an increased amount of wider NHS time is being saved than was previously the case.
- The increased clinical activity and more patients seeing MS nurses more regularly support these findings, as better support from MS nurses means it's likely patients will have to rely on other health professionals less.

- As shown in the table opposite, applying a cost to the above indicates that the MS nurse service saved approximately £74,539 in ambulatory costs in the 12 months to January 2019.
- This is calculated by applying the proportion of people who said they would have used other health services more to the overall caseload, and multiplying this by the unit cost for each service.
- This assumed each person would have one only seen their GP or neurologist, or gone to A&E once during the year so is likely to be an underestimation.



	Additional required per year per person on caseload without the MSSN service	Number avoided	Unit cost	Cost avoided across the caseload	Source for cost data
Neurologist consultations	0.330	343	£125	£42,818	NHS reference costs 2017-18
A&E visits	0.080	83	£160	£13,286	NHS reference costs 2017-18
GP visits	0.480	498	£37	£18,435	PSSRU unit costs of health and social care 2018, 18 minute consultation
TOTAL ambulatory care costs avoided				£74,539	

Impact on patient outcomes (3): The MS team have driven changes which could reduce hospital admissions, with data indicating a reduction in these (saving nearly £46,000)

Evidence of the impact on hospital admissions

It's not possible to definitively state that activity in the MS nurse service has directly caused changes in unplanned hospital admissions. Many factors such as patterns of winter illness, for example, will have played a part. However, the MS nursing team are seeing more patients for longer appointments and are more easily contactable. They therefore are able to review patients more holistically and conduct interventions which might help reduce hospital admissions. They have also instigated other specific changes which could impact on admissions, namely:

- Facilitating more referrals and access to other appropriate health professionals, including district nurses, physios, OTs and GPs (the patient survey showed people finding advice on accessing other health professionals helpful increased by 14%)
- Increased numbers of home visits (63% increase), mostly with progressive patients who are more likely to be admitted
- Joint visits with social workers meaning specialist MS advice now provided to more at risk people
- More ward visits, with notification of admission coming directly from the patient or from staff on the ward. This allows MS
 nurses to give more specialist advice, and attend MDT meetings prior to discharge. Also now a system for recording these,
 and patient survey findings indicate patients who were admitted to hospital had more visits from nurses

Evidence from the Information Services Division (ISD) of NHS Scotland and the patient survey

Data received from ISD shows that 35 people were admitted to hospital due to their MS in Lanarkshire during 2017, and that this reduced to 30 in 2018 (a 17% decrease). However, this only counts those with a primary diagnosis of MS and is therefore likely to greatly underestimate the total numbers receiving unplanned hospital care due to their MS. The patient survey found that 11% of respondents were admitted to hospital in the 12 months up to January 2019, compared to 13% in the same period to January 2018. The average number of nights spent in hospital also decreased to 6.5 from 9 nights. If these patient survey findings were replicated across the caseload:

- 114 people were admitted due to their MS in the 12 months to January 2019, compared to 135 in the 12 months to January 2018
- This led to a cost reduction of £45,929 (by applying patient survey data to ISD figures for the average cost of an unplanned hospital admission, across all specialties, in Lanarkshire,£2,206)

Conclusions

- Lanarkshire MS nurse team's involvement in the MS Trust Specialist Nurse Programme has provided an impetus for change leading to a programme of quality improvement. The service is reaching more people and providing a more accessible service (through more home visits and virtual clinics), a more responsive service (through an improved phone service) and a more holistic service (by increasing appointment times)
- More clinics with longer times for patient consultations and a range of further improvements have been made to deliver better patient care:
 - Less nurse time spent taking blood, with 17 new DMD/phlebotomist clinics a month, so MS nurse appointments increased from 15 to 30 minutes
 - New relapse and newly diagnosed clinics, as well as joint visits with social workers, better phone systems and new remote clinics
 - Better links with other health professionals, new screening forms, and relapse and steroid pathways
- This increased activity has led to improvements in patients being able to see and access MS nurses more regularly and quickly, as well as improved patient experience:
 - More patients seen more often by the MS nurses, face to face, by phone, through home visits, or in wards if admitted to hospital
 - More patients were offered annual reviews, reported being able to contact MS nurses quicker, and know when their next consultation is. Increased numbers of patients have also seen other health professionals more, supporting better coordination of care
 - This improved service has contributed towards patients reporting advice to be more helpful, particularly on accessing other health professionals, increases across measures of patient centred care, and increased satisfaction on levels of contact
- These improvements have also contributed to better patient outcomes and cost savings:
 - More people reported that the MS nurse service had a positive impact on their wellbeing. This was particularly so for people with progressive MS
 - If patient survey responses were replicated across the broader caseload we can estimate that the service saved £74,539 in ambulatory costs in the 12 months to January 2019
 - Scottish Government and patient survey data indicates fewer people with MS had hospital admissions, with many of the service's improvements supporting admission avoidance. Using patient survey data the service has saved £45,929 in reduced hospital admissions