Multiple Sclerosis Trust

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Modelling sustainable caseloads for MS Specialist Nurses
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Report on a consensus process led by the MS Trust
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1. Introduction and objectives

The MS Trust has been at the forefront of supporting, developing and mapping MS specialist nurse (MSSN) services across the UK. We published an overview of MS nurse coverage by commissioning organisation in 2012[1]. In parallel with this publication, we are publishing an updated report in the light of the recent restructuring of the NHS in England and also the advent of a new commissioning landscape[2].

In order to assess whether the number of MSSNs within each part of the UK is sufficient, it is essential to agree on what constitutes an acceptable caseload for an MS specialist nurse. The MS Trust has developed, as part of the GEMSS (Generating Evidence in MS Services) programme, a capacity planning and caseload model and, in September 2014, convened a consensus group of experts and practitioners (listed at the end of this report) to test the model and develop robust assumptions to put into it. This briefing reports on the results of that process.

The objectives of the work were:

➤ to quantify a sustainable caseload for a whole time MSSN

➤ to identify the conditions under which this might need to be varied, for example based on how rural the area covered is

➤ to identify what conditions need to be present for services to be effective with this level of caseload

2. Approach to modelling caseload

We refer to a 'sustainable' caseload because we acknowledge that any caseload figure needs to strike a balance between what is desirable on the one hand and what is realistic and achievable on the other. As a priority, we need to ensure sufficient nurse input to provide safe, high quality services, not merely reflecting current 'average' provision, which we know in some areas is overstretched or inadequate and, as a

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consequence, leaves work undone. We recognise, however, that services are operating within a resource-constrained NHS, where efficiency and productivity are of paramount importance. To achieve this balance, we have adopted two approaches and sought to bring them together through an iterative process:

1   'Bottom up' modelling, looking at what people with MS need from an MS specialist nurse in terms of face to face contact and associated activities, and creating job plans to deliver this
2   Looking at real world examples of MSSN services and what they are achieving in terms of the outputs they deliver and the caseloads they manage

Work by Professor Alison Leary undertaken for the MS Trust in 2011[3] modelled specialist nurse caseloads based on a review of published evidence and interviews with eight MSSNs. Our new model builds on that work, but the assumptions are informed by data now available through the GEMSS programme. In GEMSS, the MS Trust is working with 16 MSSN teams across the UK to evaluate and improve their services. This has allowed the Trust to develop a unique insight into the way in which MS specialist nurses work in different settings and the factors that influence their effectiveness. The GEMSS teams represent 40 specialist nurses with a combined caseload of 17,500 patients (over 16% of all people with MS in the UK). These teams have collected, or are currently collecting, a year's data about their caseloads, activity, performance against key process indicators and patient outcomes (measured through a patient survey, health professional survey and case studies). A full report on the programme will be published in late 2015, but interim analysis of GEMSS data was used to test the 'real world' validity of the assumptions.

3. Assumptions in the model

The model is based on a set of agreed assumptions about MSSN services.

3.1 Service model in terms of the trajectory of MS

MS Specialist Nursing - 2014: the case for equitable provision[2] describes the trajectory of different types of MS and explains the importance of specialist nurse input at different points in the pathway. The caseload model derives the sustainable caseload for an MSSN (or MSSN team) providing an 'end-to-end' service – that is, a service to people along the whole trajectory of MS from diagnosis to end of life.

While most services (based both in hospital and community settings) operate 'end-to-end', the GEMSS project has highlighted some alternative service models. In some areas, two different types of services operate, serving different patient populations. Here, patients with progressive MS and complex needs are looked after by MS nurses, usually based in the community, who focus on this part of the trajectory. People with MS who are more recently diagnosed and/or in the relapsing remitting phase of the disease may then be cared for by a separate team, usually based in a hospital. In practice, services often cut across these models with, for example, a hospital team looking after everyone with MS in part of their 'patch' but only relapsing remitting MS patients in another part. For the purposes of modelling the need for MS nurses at a population level, looking at sustainable caseload for 'end-to-end' services is the most useful, but care should be taken when applying the results at a local level to look at the model of provision.

3.2 Service standards to meet the needs of people with MS

The newly published NICE guideline on MS[4] makes several recommendations for service standards which may fall within the remit of MS specialist nurses, including, for example: providing oral and written information about MS at the time of diagnosis (recommendation 1.2.2), advising people with MS about exercise (recommendation 1.4.1), offering decision support around pregnancy (recommendation 1.4.6) and ensuring people with MS have a comprehensive review of all aspects of their care at least once a year (recommendation 1.6). However, the guidance is notably silent on which professional should deliver the recommended aspects of care and on specific standards for MS specialist nurse services.

The following core standards of care for MSSNs (see box) were developed within the GEMSS programme and validated by the consensus group. All are being monitored by teams participating in the GEMSS programme. They were informed by a review of policy documents and other evidence, including the earlier 2003 NICE Guideline on MS[5], the Neurological Conditions National Service Framework[6] and the Neurological Health Services Standards for Scotland[7] (standards marked with * reflect the Scottish service standards), and then refined through a consensus process with the participating GEMSS nurses and GEMSS advisory group[‡].

Core service standards for MS Specialist Nurse Services

➤ People with MS should have continuous access to an MSSN from diagnosis to end of life (i.e. they are not discharged from the service unless another team is taking them on) and have a face to face review with an MSSN, at least annually.*

➤ Face to face consultations should take place in the setting most appropriate to the person with MS. The options should include home visits for those who need them according to a defined protocol (for example including patients who are confined to bed or whose home situation needs to be assessed).

➤ People with MS should be able to access the MSSN service by telephone, and receive a call back within 2-3 working days, or the same working day if they are experiencing a relapse or acute deteriorating symptoms. Some services are also offering email and text message options.

➤ Patients experiencing relapses or acute deteriorating symptoms should be offered an expert assessment (which could be in a dedicated relapse clinic) and have treatment promptly, within 5 working days of contact.*

➤ Everyone newly diagnosed with MS should receive a timely holistic assessment from an MS specialist nurse within 2 weeks of referral where they can be offered information and support.*

➤ Everyone newly diagnosed with MS should be invited to attend a structured patient education programme (such as the MS Society 'Getting to Grips with MS' course).* Over and above this, many teams also offer other group education programmes such as fatigue management courses.

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‡ See www.mstrust.org.uk/gemss for details of the Advisory Group

3.3 Consensus on the input from MS specialist nurses needed by people on the caseload

Analysis of the GEMSS teams' patient experience survey data shows a clear correlation between the amount of contact received by people in the caseloads and their feedback that this level was enough. The following assumptions were agreed for the model based on expert opinion and validated with reference to real world GEMSS team data:

➤ Patients do not, or only very rarely, require MSSN input prior to a formal diagnosis of MS. A small proportion of patients are diagnosed with Clinically Isolated Syndrome (CIS)§, but it is assumed that these do not receive input from an MSSN unless they are prescribed a disease modifying treatment.

➤ In the first year of diagnosis with MS, patients will require more intensive support than in subsequent years (on average **1.5 additional consultations**).

➤ Patients on the caseload will, on average, require **2.4 face to face consultations** with an MS nurse each year, to encompass both planned reviews and urgent consultations for relapses and deteriorations. Within this average there will be a great deal of variability between individuals, with some patients needing multiple consultations and others the minimum of one annual review. The consensus group agreed the following averages required for face to face consultations for different types of patients in a typical caseload, to deliver high quality care:

Average MS specialist nurse input required by case type: consensus estimate

Case type	Average face to face contacts with an MSSN per year	Estimated proportion of caseload for an 'end-to-end' service*
Relapsing remitting MS, not on DMTs	1.5	17%
Relapsing remitting MS or CIS, on DMTs	2.5	42%
Progressive MS	2.5	41%
Newly diagnosed (additional consultations in year 1)	1.5	5%
Overall face to face contacts per person per year (all patients)	**2.4**	

§ CIS is the result of a single episode of demyelination in one area of the central nervous system (a monofocal episode) or several areas of the central nervous system (a multifocal episode) which lasts for at least 24 hours.

* The percentages add up to 105% because the 5% who are newly diagnosed are also contained within the other categories

> **The proportion of face to face consultations which are carried out as home visits is assumed to be 15%**. This is a challenging assumption, as the home visit rate amongst the GEMSS teams is, on average, higher than this. However, with appropriate policies in place and availability of sufficient clinic space it was considered to be achievable (except in very rural areas, discussed below).

> **People with MS on the caseload will, on average, telephone the service 2.9 times per year**. This reflects GEMSS team data.

3.4 The MS Specialist Nurse working week

As the earlier work by Alison Leary identified, the MSSN working day is a five phase day typical of most specialist nurses[8]. This indicates a mixture of clinical activity, clinical case management and administration. The clinical work occurs not only face to face (in nurse led clinics, drop-in sessions, joint neurology clinics, patient education sessions and home visits) but also by telephone (and sometimes text and email). Telephone work (both directly with patients and in making referrals and brokering care) constitutes a major element of nurse activity: analysis of GEMSS phase 1 teams' work using the Cassandra tool** showed that 42% of recorded nursing 'events' (both with patients and other professionals) took place on the telephone[9].

Other important additional elements of the role besides direct one to one patient interaction include:

> Attending case conferences and multidisciplinary team meetings, providing specialist contributions to Continuing Healthcare Assessments and assisting in the development and monitoring of personal health budgets
> Up-skilling other health professionals (such as GPs, allied health professionals, ward nurses and nursing home staff)
> Planning and developing group education sessions
> Service development and audit
> Clinical administration, including assessing and communicating test results and discharge planning for patients admitted to hospital

For this reason, the consensus group determined that face to face patient contact time would constitute half of the working week (five clinical sessions), with the remainder for other clinical work and professional and service development activities: a proportion that reflects our GEMSS teams' job plans on average.

An assumption was made that MSSNs work 42 weeks a year to allow for mandatory training, continuous professional development, annual leave and bank holidays. This is in line with NHS reference cost calculations[10].

** Cassandra is a data collection tool which enables nurses to record and analyse how they spend their time. Further information about it is available at: http://www.apollonursingresource.com/showing-how-i-spend-my-time/cassandra-app/

4. Putting it together: results of the model

Applying the assumptions outlined above, we constructed a model to derive a caseload figure. Based on the model, a manageable caseload for a full time MSSN working across the whole disease trajectory and delivering a service based on a specified job plan is 358.

However, this finding is subject to some important conditions, discussed in the next sections.

The job plan represented in the model for a full time MSSN would consist of the following:

Type of sessions	Number of sessions per week (out of 10)	Outputs in an average week when at work (i.e. excluding leave)
Outpatient clinics	3.5 sessions (i.e. 3 / 4 on alternate weeks)	17.5 outpatient consultations per week
Home visit sessions	1.5 sessions (i.e. 1 / 2 on alternate weeks)	3 home visits per week
Telephone and email work All other elements in the role, identified in section 3.4	5 sessions per week	Dealing with 21 incoming calls from patients and carers each week

Formal training and CPD activities, and additional roles (such as research and team management) are not included in the job plan (see section 5 below).

There are circumstances in which the model findings will not hold and the caseload figure will require adjustment. These are as follows.

4.1 Exceptionally rural areas

The model assumes that the area covered by the service is not exceptionally rural. If in fact it is[††], this would affect the sustainable caseload in two ways. First, it might mean a higher proportion of face to face contacts carried out as home visits (because patients find it harder to reach a clinic). Secondly, it would mean fewer home visits achievable per session. In such areas, there are opportunities to use telehealth to deliver some consultations remotely. Nevertheless, our model suggests that in these types of areas, a caseload of around 250 patients is more realistic, assuming a higher home visit rate of around 25% and only one home visit achievable per half day session. In island localities (such as the Hebrides and Shetland) travel times and logistics are an additional factor and both the job plan and caseload would require further adjustment.

†† As a guide, 31 out of the 211 CCGs in England, 10 of the 14 Health Boards in Scotland, 1 of the 7 Health Boards in Wales and the country of Northern Ireland all have a population density of less than 2 people per hectare, which could be defined as exceptionally rural.

4.2 Alternative service models

Across a caseload of 358 patients, there will be a wide range of needs, with some patients requiring only an annual review and others much more intensive input at key points in the trajectory of MS. These key points are described in more detail elsewhere[2]. This variability is already taken account of in the model. However, in areas where the services are not 'end-to-end', but MSSNs focus on particular parts of the disease trajectory, a local modelling exercise would be needed to assess how many patients could be handled by each service. Services focusing on progressive MS would expect a higher home visit rate and lower caseload due to the higher dependency levels, and conversely services focused on the earlier parts of the trajectory could potentially handle a slightly greater number. As part of the GEMSS programme, capacity planning workshops can help local teams to assess their own capacity to deliver a service to their local population given the particular way that their service is configured.

5. Important conditions for effective service delivery

The model assumes that MSSNs operate at a high level of efficiency. However, there are a number of important conditions which need to be in place to enable this to happen, and if they are not met then the 'sustainable' caseload identified will not be achievable. Based on GEMSS teams' experience, service features which are needed are as follows:

➤ **a proactive service**: In order to target their limited time effectively, MSSNs need systems for proactively case-managing the people on their caseload. They should stratify them according to how frequently they need to be reviewed based on an assessment of risks and issues. A 'one size fits all' approach will mean that those who need the most input don't necessarily receive it which may lead to the service becoming 'reactive' – responding only to those in crisis and neglecting the planned reviews that could prevent crises occurring or escalating.

➤ **an effective home visit policy**: Achieving a home visit rate as low as 15% of face to face contacts will require a clear policy, meeting the Quality Innovation Productivity and Prevention (QIPP) framework, to ensure that visits are targeted only to those that need them, and sufficient clinic space to ensure that home visits are not substituted for clinic sessions due to constraints on outpatient facilities.

➤ **sufficient administrative support**: Data from GEMSS[9] and elsewhere[11] highlights that specialist nurses can spend a large proportion of their time undertaking routine administrative tasks, such as filing, typing letters, answering non-clinical phone enquiries and requesting blood results, which represents an inefficient use of their specialist expertise. MSSNs need the support of either an administrator or support worker to free up their time for specialist care.

➤ **'smart' scheduling**: High levels of productivity require a high level of utilisation of outpatient and home visit slots. Again, an administrator or support worker can play a key role in grouping home visits to minimise travelling time and working with reminder systems to reduce the DNA ('did not attend') rate and ensure that any cancelled appointments are reallocated. Teams should regularly review their utilisation of clinic slots to ensure that they protect sufficient, but not too many, 'urgent' appointments for relapses and other urgent needs. Telephone triage can be used innovatively to determine whether patients need planned reviews before booking them in (although an annual face-to-face review for all people with MS, as

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recommended by NICE[4], remains a minimum). Having basic data collection systems in place (such as those described in *Defining the value of MS specialist nursing*[1] and provided through the GEMSS programme) is an important pre-requisite to enable services to be planned effectively, and flexible clinical information systems are an important enabler.

> **availability of prescribing**: Some MSSNs are qualified nurse prescribers, others are not. The consensus group decided that there is insufficient information to make a judgement about whether being a nurse prescriber on balance saves nurse time, or whether it means that more time is needed (in exchange for a smoother prescribing process). However, what is clear is that if MSSNs are not prescribers, they need ready access to medical staff who can make the prescribing decision in response to their recommendations about symptomatic therapies and other treatments.

> **clinical supervision**: Clinical nurse specialists benefit from support to help with complex case management and relieve the emotional pressure that builds up when they spend so much time absorbing other people's distress. To build a sustainable service, there need to be systems that preserve and value the emotional commitment of nurses to their work. This also has the benefit of increasing staff retention and reducing sickness[12].

> **additional, dedicated time for commitments beyond the MSSN role**: The model does not include time for additional roles such as managing a wider team of clinical nurse specialists or undertaking research. If these are included, it will mean a reduction in the sustainable caseload.

> **support for injection training**: In most areas, support nurses funded by pharmaceutical companies are available to train patients in using self-injected disease modifying therapies. The model assumes that these are available. If they are not, then a modest decrease in the caseload will be required.

Through the GEMSS programme, the MS Trust plans to publish 'good practice consensus guides' on a range of these topics, over the next 12-18 months.

6. Conclusion

The MS Trust model shows that, for the purposes of planning MSSN services at population level, a caseload of 358 people with MS per nurse is an appropriate number to use, except in very rural areas. However, care needs to be taken to ensure that the service is working efficiently and that the conditions identified are in place to enable this level to be sustainable.

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