**Title Page**

Modelling the Multiple Sclerosis Specialist Nurse Workforce by determination of optimum caseloads in the United Kingdom.

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**Key Words**

Multiple Sclerosis, Specialist Nurse, Workforce, Modelling, Caseload

**Practice Points**

* The work of Multiple Sclerosis CNS in the UK is complex and is the principle means of case management in the care of people with MS.
* There is no simple figure in terms of optimum caseload as the workload is variable depending on a number of factors
* The current recommended UK caseload of 358 per whole time equivalent appears to be too high with a considerable amount of work left undone. This has been revised downwards to 315.

**Abstract**

**Background**

It is estimated that there are over 100,000 people in the UK who have Multiple Sclerosis. Access to a specialist nurse service improves patient experience and outcomes. The aim of this study was to publish a new, robust validated standard optimising the UK nursing workforce model.

**Methods**

Existing national data and specific workload and service data were collected from 163 multiple sclerosis specialist nurses who completed a questionnaire to collect information on activity and complexity of work both done and left undone.

**Results**

Data was received from all of the UK. Twenty-nine percent of respondents were specialist nurses in the field for three years or less. Unpaid overtime was regularly carried out by 83.4% of respondents. The multiple sclerosis specialist nurse was involved in all areas of the patient journey. Areas of work left undone were psychological interventions, physical assessment, social interventions/ benefits and recommending or prescribing medication.

**Conclusions**

The current recommended caseload of 358 per whole time equivalent appears to be too high with a considerable amount of work left undone, particularly psychosocial care. Factors such as travel time, complexity of caseload, changing drug therapies and societal issues such as the benefits system contributed to driving demand/workload. Title: Modelling the Multiple Sclerosis Specialist Nurse Workforce by determination of optimum caseloads in the United Kingdom.

**Introduction**

One of the most important challenges for the NHS in the UK and healthcare worldwide is to accurately calculate both the expertise and amount of time nurses require to care for different patient groups in a variety of environments. It is difficult to do this because nursing, in common with most human activities, is complex1,2 and dynamic. As a result, clarity over which information is even relevant to a proposed model may be challenging3.

Despite the complexity of nursing work most approaches to examining the work carried out by nurses view their actions as a simple linear series of tasks4.

It is estimated that there are over 100,000 people in the UK who have multiple sclerosis (MS)5. This estimate is based on work by Mackenzie6. The same study suggested that the number of people in the UK with MS was growing at 2.4% per year due to people with MS living longer.

According to a recent report by NHS Digital, in England 120,786 hospital admitted patient

care episodes occurred from 2016 to 2017 for patients with a diagnosis of MS with nearly half, (54,732, 45%), of these episodes having MS as their primary diagnosis7.

In 2014 the MS Trust published caseload guidance based on consensus for MS specialist nurses (MSSN) in the UK8. This recommended 358 people with MS as a caseload per whole time equivalent MSSN. As services and demands have changed, this figure requires review. One of the drivers for this is the increasing treatment options which require extra resource such as supporting patients with shared decision making, patient education and monitoring.

Specialist nursing work varies in the UK. The level of practice and job title for example are not a reliable proxy for complexity of practice9. This means that nurse specialists in the UK tend to work at a range of levels of complexity, offer a different range of interventions and do so within many different service arrangements. These factors can affect workload burden. Other factors include complexity of patient needs10 and access to members of the multidisciplinary team11 (MDT).

The aim of the study was to carry out demand modelling to understand the need for MS nursing interventions and by doing so inform modelling the future UK MS nursing workforce. This included understanding how the current workforce meets demand, what work is left undone, how much overtime (paid and unpaid) is required to meet demand and the available skill mix in terms of complexity.

**Methods and Data Collection**

**A priori dataset- complexity and factors that affect workload**

A curated dataset of around seventy million hours of advanced practice specialist work (n=18,000) since 2009 was accessed to look at patterns and workload of other specialists working in long term conditions. These data reflect varying levels of complexity of work and have generated indicators of workload in order to use stochastic approaches to optimum caseload calculation. From this curated data set a number of common factors which typically influence specialist nurse workload were determined. Examples of such factors included relationships with other members of the multidisciplinary team11, complexity of caseload12, 13, access to administrative assistance14, access to other services15 and education and experience16. Issues such as access to non-medical prescribing17 and the ability to independently request investigations were also significant factors. Where nurse specialists are able to prescribe and independently request investigations this enables and empowers them to make independent decisions rather than “door hang” (for example waiting for a clinician to approve prescribing medication or ordering investigations) for the decisions of others.

**Consensus workshop of expert opinion-checking the assumptions**

In order to use the existing a priori dataset and the on-line data collection tool it was necessary to check the assumptions made regarding the workload and activity of this group.

A consensus workshop of 13 MSSN from across the UK was convened to check and challenge assumptions drawn from the dataset. The nurses were asked to explain their work in detail. Areas examined included the work environment, physical and psychological domains, social issues, case management, administration and work left undone. The MSSN had a similar work pattern to those in other long-term conditions such as inflammatory bowel disease13 and rheumatology16 apart from two issues which were raised by the attendees. One issue was the amount of time spent travelling, especially in rural practices. The second issue was the impact of patient’s benefits claims on workload. In order to investigate these issues two additional questions were added covering these areas to the previously employed questions.

**Data collection specific to MS**

A 24-item questionnaire, exploring demographic data, caseload and workload was developed for this population by consensus using clinical, patient and academic experts based on a previously employed national study13. The questionnaire was designed to gather data on activity and complexity of specialist nursing services provided including work left undone and used a format similar to the national optimum caseload modelling project developed by the National Cancer Action Team Alexa caseload tool first used in lung cancer and subsequently in other long-term conditions15. This was transferred to an online survey tool (administered using a Survey Monkey secure account). The survey link was distributed through the Multiple Sclerosis Trust and other professional mailing lists such as the UK Multiple Sclerosis Specialist Nurse Association (UKMSSNA) during July 2018. One hundred and sixty-three participants responded to the questionnaire. A single response could only be submitted from each computer. Analysis of the survey took place in September 2018.

**Data analysis**

Data were exported into Excel and modelled using descriptive statistics for example demographics, pay band and length of service, workload, interventions delivered, work left undone and educational background. Free text comments were analysed using NVIVO 11 and thematic content analysis20. Thematic content analysis is the approach best suited to free text questions in an otherwise quantitative questionnaire as it does not rely on interpretation of data but instead reflects a ‘low hovering over the data’. Demand modelling (causal) was done using Mathematica V10.

**Caseload calculations**

Responses to the Survey Monkey workload questionnaire were received from 163 nurses who completed the questionnaire in whole or in part. The total population of MSSN in the UK is estimated to be around 290 by headcount (Source: MS Trust) so this equates to an approximate 56% response rate.

The data sets were then used to construct a demand model focussed on workload. This included work that was necessary but not done. This approach uses a combination of qualitative and causal modelling which looks at the real-world experience of workers and past trends. Once the demand, including the deficit had been determined, the supply (caseload calculation range) was determined.

**Results**

**Respondent’s Demographic Data and Epidemiology of MS in the UK**

The country of practice, number of hospital sites covered, number of hours worked per week, unpaid overtime worked per week (including working through meal breaks), type of practice, length of time working with MS patients, and educational qualifications are summarised in Table 1. The 163 respondents to this question represent approximately 139.8 FTE based on the median contracted hours per week reported. The amount of unpaid overtime worked by respondents equates to approximately 664 hours of unpaid overtime worked per week in total by respondents as a whole (assuming median values of 2, 5.5, 8.5 and 10 hours extra for the four categories reporting unpaid overtime) or 4.07 hours each which is equivalent to approximately 17.2 FTE unpaid overtime being worked per week in total.

***Insert Table 1 here***

**Time spent travelling between sites or making community visits**

The amount of time respondents spent per week travelling between different hospital sites or making community visits was examined. Respondents were asked not to include time spent commuting to and from their place of work in this estimate. Only 36 (22.1%) of respondents did not spend time travelling. 44 (27%) spent less than two hours per week, 48 (29.4%) between two and four hours, 22 (13.5%) between 4 and 6 hours and 13 (8%) more than 6 hours.

Using the median travelling time for each group this equates to 363 hours travelling time per week for the whole group.

Travelling time was then compared with the type of practice (rural, urban or mixed) and is shown in Figure 1.

***Insert Figure 1 here***

There appears to be an association with having a rural practice or a mixed rural and urban practice and time spent travelling.

**Administrative Support Provided to Respondents**

Respondents were asked how much administrative support (help with typing letters or doing routine non-clinical administration) they received each week.

Fourteen percent responded that they received no admin support at all. A further 26% responded that they only received admin support for clinic letters.

Of the respondents who did receive admin support to use as they wished 10% received between 1- and 5-hours’ support, 12% between 6 and 12 hours, 13% 13 to 20 hours and 25% more than 20 hours per week.

**Unfilled and Frozen Vacancies**

To ascertain the level of unfilled and frozen posts (frozen posts are those which are currently vacant but not being actively recruited to usually for financial reasons), respondents were asked how many, if any, posts were unfilled in their speciality. Seventy-six percent of respondents had no unfilled posts. 10% of respondents had less than one FTE unfilled while another 10% had one FTE unfilled. Finally, 5% of respondents had two FTE unfilled and 1% five or more posts. One respondent reported frozen posts.

This equates to approximately 35 FTE posts unfilled in total from this population.

**Respondents Estimated Caseload**

Respondents were asked to estimate their individual caseload. 34% of respondents had caseloads over 500 patients while only 26.9% had caseloads of 300 or less (Figure 2). Taken as a whole this represents an approximate total caseload of 73,750 patients for all 156 respondents.

***Insert Figure 2 here***

**Respondents Work Done**

Respondents were asked if they carried out certain tasks at each level of the treatment pathway (Pre-diagnosis, diagnosis, post-diagnosis, treatment and end of treatment/follow up).

It can be seen that as a group MSSN are involved in all stages of the treatment pathway. The responses are summarised in Supplementary Figure 1.

***Insert Supplementary Figure 1 here***

The six most common interventions at each treatment stage are shown in Figure 3. The most common tasks throughout the treatment pathway were meeting information needs, symptom control, referrals, psychological interventions and social interventions/benefits advice.

***Insert Figure 3 here***

**Respondent’s Sessional Work**

A total of 1547 sessions per week were recorded by all respondents. Provision of an advice line accounted for 565 sessions (36.5%), nurse-led outpatient clinics 389 sessions (25.2%), telephone clinics 277 sessions (17.9%), inpatient working 121 sessions (7.8%), joint clinics 84 sessions (5.4%), consultant lead outpatient clinics 63 sessions (4.1%) and virtual clinics 48 sessions (3.1%).

**Respondent’s Work Left Undone**

Psychological interventions, physical assessment, social interventions/ benefits and recommending or prescribing medication feature highly in respondents work undone. Work left undone is summarised in Figure 4.

***Insert Figure 4 here***

**Respondents time spent dealing with benefits claims**

Respondents were asked how long they spent on average each week dealing with a number of benefits which MS patients might claim (Universal Credit, Personal Independence Payments, Attendance Allowance, Employment and Support Allowance, Carers Allowance and ‘Other’). There was also a free text option for further comments from respondents.

Of the respondents who spent time on benefits claims in general 132 spent at least some time on Personal Independence Payments, 96 on Employment Support Allowance, 64 on Carers Allowance, 63 on Attendance Allowance and 44 on Universal Credit. 35 reported spending some time on other benefits. This is summarised in Supplementary Figure 2.

***Insert Supplementary Figure 2 here***

A number of themes emerged from analysis of the 48 free text responses received.

Writing reports and letters of support were mentioned 19 times with a typical example being:

* *“support letter for employers and early retirement on health grounds. Also for grant applications and continuing care assessments”*

Eight responses concerned being unable to write reports or letters of support either through lack of time or being informed not to by their Trust. An example included:

* *“I do not assist in writing reports for PIP and other benefits at this time due to the size of the caseload”*

As regards referring MS patients to other agencies for support with benefits, nine comments mentioned the Citizen’s Advice Bureau (CAB), four mentioned charity supplied advisors and two social workers. A typical example being:

* *“I will write reports when asked from relevant agency. We work closely with MS society who pay for a CAB advisor to be available one day a week at the MS therapy centre to discuss all these issues and to help individuals complete forms, plus support them through the appeal process if needed. This is an invaluable service and relieves the nursing service of a significant amount of workload.”*

Comments also raised the distress and anxiety caused by PIP, for example:

* *“Rolling out PIP in my area so have had marked increase in requests to assist with form filling, providing evidence, requests for a review and dealing with anxiety and caused by the process.”*

Other similar issues which took up respondent’s time and were mentioned in comments included MS grants, support at work, DVLA and Blue Badge requests, issues related to education and housing adaptations.

**Discussion**

Specialist disease specific nurses are known to enhance the quality of care and patient experience19, 20 and can be productive not only in terms of quality but also in terms of efficiency such as the avoidance of unnecessary admission to an acute inpatient unit14, 21. As with any supply model there is likely to be a point of saturation whereby the quality of the service is at least partly driven by the distributed workload which can result in work being left undone22.

There are some limitations to the study including obtaining data from a self-selecting group via an online survey, reliance on a priori data from workers outside the MS speciality and that the model was a retrospective “one point in time” model and relates only to the situation encountered by respondents. If the respondents workload radically changes this model will have reduced reliability.

The spread of respondents throughout the UK is similar to that found in the recent MS Trust Nurse Mapping Survey which reported 81.5% WTE of MS nurses were in England, 10.8% in Scotland, 4.8% in Wales and 2.9% in Northern Ireland23.

Caseloads as high as 2000 patients plus were reported. There are a number of potential reasons for these high caseloads. One potential issue is unfilled MSSN posts. In this study the number of unfilled posts reported by respondents is estimated to be equivalent to 35 FTE. Another factor which is apparent from the study is the amount of unpaid overtime currently being carried out by MSSN. Only 17% of respondents regularly carried out no unpaid overtime. The amount of unpaid overtime carried out by the remaining respondents equalled an estimated 17.2 FTE.

It is clear from the workload analysis that there is much variability and different levels of service provision. The group recorded 1,547 sessions which were taken up with programmed clinical activity. The majority of this time was a telephone advice line (565, 36%) and nurse led clinics (389, 25%).

It is also apparent that because of the variability of service provision, local circumstances should be taken into account such as the availability of administrative help which remains a burden for some MSSN. In other specialisms the provision of administration and support workers has increased productivity for example administrative workers allowed multiple sclerosis specialist nurses to proactively manage their case load resulting in reduced emergency admission24. Another local factor which can influence caseload is the complexity of patients.

The amount of time spent by MSSNs on MS patient’s benefits claims appears to be significant with all of the various UK benefits examined in the study taking up MSSN time. Anecdotal evidence from the analysis of the free text comments suggests that there are other social issues such as interaction with the Driver and Vehicle Licensing Agency regarding the ability to drive, Blue Badge applications (the disabled parking scheme in the UK), reports required by employers, housing and education all adding to the MSSN workload.

The previous work by the MS Trust cited a recommended caseload of 358 per whole time equivalent (WTE) MSSN. Anecdotal evidence from the MSSN population indicates that caseload and workload are increasing.

In terms of caseload, one of the reasons for this could be that the data is underestimating the population. It is surprising that, to date, there is no accepted accurate figure for the number of people with MS in the UK and this is an area which requires further investigation. Anecdotally there are also changing demands on the system, which, along with population increase, are likely driving workload increases. The drugs regimes are becoming more complex with greater risks and as a result people with MS require more complex monitoring; structural and societal issues such as changes to the benefits system are also causing an increase in workload.

At the current recommended caseload range, a considerable amount of work is left undone. This is particularly so of psychosocial care, symptom control and medicines management. Less than 30% of this group were independent prescribers which leads to door hanging-having to access other professionals to sign off decisions or recommendations. Previous work has shown that it is generally more efficient if case managing advanced practice nurses can sign off their own prescriptions and investigations.

A caseload closer to 315 is more realistic in terms of delivering care within this envelope but this is not absolute and should consider the following factors:

This figure is based on the average for the group. 5-10% of the caseload is complex and requires approximately 30% of the available time. More complex caseloads should be adjusted to reflect this for example more co morbidity, symptom control issues or very high psychosocial needs. If such patients (requiring two hours a week or more MSSN time) are higher than 10% of the caseload then the figure should be adjusted downwards proportionally.

**Conclusion**

Given that the work left undone is considerable, the complexity of work has increased and the caseload mixed, the original recommendation of 358 is on average too high to optimally manage care. Factors such as travel time, access to psychological care, complexity of caseload, changing drug therapies and societal issues such as the benefits system contributed to driving demand/workload.

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**Conflict of Interest Statement**

GH and MR are employed by the Multiple Sclerosis Trust. No other conflicts of interest are reported.

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**Figure Legends**

Figure 1: Respondents time spent travelling (hours) between sites or making community visits compared to rural, urban or mixed practice types.

Figure 2: Respondents annual caseload (156 responses). The bar in blue (301 to 500 caseload) indicates where the previously recommended caseload of 358 lies. The bars in green indicate where this caseload is exceeded.

Figure 3: The six most common areas of intervention left undone at each stage of the treatment pathway.

Figure 4: The six most common interventions at each stage of the treatment pathway.

Supplementary Figure 1: Respondents work done (134 responses). Respondents could choose multiple options.

Supplementary Figure 2: Respondents time spent on benefits claims per week (148 respondents). Key: UC; Universal Credit, PIP; Personal Independence Payment, AA; Attendance Allowance, ESA; Employment Support Allowance, CA; Carers Allowance.

**Tables**

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| --- | --- | --- | --- | --- | --- | --- |
| **Respondents Country of Practice** | | | | | | |
| **England** | **Wales** | **Scotland** | | **Northern Ireland** | | **Eire and other** |
| 76% (124/163) | 4% (6/163) | 14% (22/163) | | 4% (7/163) | | 2% (4/163) |
|  | | | | | | |
| **Respondents Demographics and Epidemiology** | | | | | | |
| **Number of Hospital Sites Covered1** | | | | | | |
| **Acute & Community** | **Community only** | **One** | **Two** | **Three** | **Four** | **Five plus** |
| 27% | 14% | 24% | 15% | 10% | 3% | 7% |
| **Contracted Hours of Work** | | | | | | |
| >37.5 | 36 - 37.5 | 31-35 | 26- 30 | 21- 25 | 16-20 | 7.5-15 |
| 3.1% | 55.8% | 2.4% | 16% | 16% | 5.5% | 1.2% |
| **Unpaid Overtime Worked Regularly per Week (Hours)** | | | | | | |
| None | 1 to 3 | 4 to 7 | | 7 to 10 | | >10 |
| 17% (27/163) | 34% (55/163) | 34% (55/163) | | 10% (16/163) | | 6% (9/163) |
| **Length of Time Working with MS Patients** | | | | | | |
| * **1 year** | **1 to 3 years** | **4 to 6 years** | | **7 to 10 years** | | **< 10 years** |
| 8% (13/163) | 21% (34/163) | 17% (27/163) | | 10% (16/163) | | 45% (73/163) |
| **Type of MS Practice** | | | | | | |
| **Rural** | **Urban** | **Mixed Urban & Rural** | | | | |
| 8% (13/163) | 32% (52/163) | 60% (98/163) | | | | |
| **Respondent’s Qualifications** | | | | | | |
| **RGN** | **RN Degree** | **RN Diploma** | | **Prescribing Qualification** | | |
| 66% (108/163) | 39% (63/163) | 34% (56/163) | | 29% (47/163) | | |

**Table 1:** Respondents background characteristics’ (1 Hospital sites were taken to include all types of hospital such as acute, community etc).



Figure 1



Figure 2



Figure 3



Figure 4



Supplementary Figure 1



Supplementary Figure 2