Defining the value of MS Specialist Nurses

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Foreword

MS specialist nurses matter greatly to people with MS. The recent audit of MS services, undertaken by the MS Trust and the Royal College of Physicians confirms this, with many comments from people with MS and healthcare colleagues praising the MS specialist nurses and the care they provide.

It is vital, though, that the MS specialist nurses are able to demonstrate their value. The reforms to the NHS, rising financial pressures and the need to deliver significant savings with no compromise in quality means that MS services need to make themselves visible to a new group of clinical commissioners and show the difference they make.

The MS Trust has commissioned this work, Defining the value of MS Specialist Nurses, to advance our understanding about the opportunities and challenges in showing the real impact of MS specialist nursing services. MS services have developed significantly over the past 15 years, and need to be ready to make a renewed case for their value.

The report makes a series of important recommendations for future work, including:

- To describe clearly the different service models currently operating amongst different MS nurses and how these fit with the long term conditions agenda.
- To define clearly what is meant by ‘caseload’, make explicit the assumptions underpinning the idea of an acceptable caseload, and define what this is, according to service model.
- To share good practice across the MS nursing community in terms of efficient and effective working practices.
- To develop a set of ‘SMART’, evidence-based quality standards for MS nursing services, against which performance can be measured, together with an effective tool for measuring patients’ experiences.
- To up skill MS nurses in evaluating their services through data collection, clinical audit and measuring the patient experience.
- To bring together data on the value of MS specialist nurses to make a robust case to the commissioners of the future.

The MS Trust remains fully committed to the MS Specialist Nurses as well as the other specialist services on which people with MS rely, including therapists, neuropsychologists and specialist neurologists. We know how important these services are to people with MS and we will continue to support, campaign for and generate evidence about the difference they make every day.

Pam Macfarlane, Chief Executive, MS Trust

Introduction

This report is about the value of Multiple Sclerosis specialist nurses. It is intended for all members of the MS community, including MS patient organisations, those responsible for managing and commissioning MS services, neurologists and specialist nurses themselves. It assesses the case for the value of MS nursing and outlines the work needed to strengthen this case further.

Multiple Sclerosis affects around 100,000 people in the UK[1]. MS specialist nurses play a vital role in helping people manage the complex and unpredictable symptoms of MS and the medication they may take for it, and coordinating the services that they need.

There are currently around 270 MS specialist nurses working in the UK[2]. However, in spite of the significant increase in MS nursing posts in recent years, there are not enough to meet the needs of people with MS throughout the UK. Some areas appear relatively well resourced, others are struggling with heavy nurse caseloads, while, elsewhere, people with MS have no or very limited access to MS nurses.

The economic environment is presenting additional challenges for MS nurses. The NHS must deliver an unprecedented £20 billion in efficiency savings by the end of 2014/15. The current financial settlement for the NHS is very tough, particularly given the pressures created by rising demand, new technologies (including new therapies for MS), and changes in demography. The Royal College of Nursing (RCN) reported that during the NHS financial crisis of 2005/6, specialist nurses were one of the groups worse affected[3], and their current Frontline First campaign is highlighting cuts in nursing services.

MS nurses are already feeling the impact. 10 out of 71 respondents in a recent survey[4] of MS nurses by the UK Multiple Sclerosis Specialist Nurses Association (MSSNA) said that their posts were at risk. In the same survey, 49% of MS nurses said that they had been asked to cut or change their services. This included having to work on wards, capping the number of patients receiving disease modifying therapy by intravenous infusion, and reductions in administrative support. The MS Trust is also aware of examples of delays and uncertainty in filling vacant posts.

At the same time, MS nurses face an era of uncertainty as far-reaching structural reforms to the NHS are introduced. The Government set out the vision for these reforms in its White Paper Equity and Excellence: Liberating the NHS (2010) and is currently looking to enact them through the Health and Social Care Bill. The first wave of pathfinder clinical commissioning groups is already in place, and the new NHS Commissioning Board has been created. The MS community needs to marshal its arguments now, to convince the new commissioners of the value of retaining and expanding specialist nurse services.

In this context, the MS Trust commissioned Geraldine Mynors and Sarah Perman of Mynors Suppiah Ltd, along with Martin Morse, to undertake a study to assess the evidence of the value of MS specialist nurses. Specifically, this explored:

- The **history of the development of the MS role** and the range of **work they undertake today**.
- The **number and location of MS nurses** and the **caseloads they manage**.
- The **arguments which drive the employment decision**, as well as **other enablers** and the **barriers**, where these exist

- How **incentives and guidelines** operating in the NHS influence the decision
- Similarities and differences in the roles and economics of MS nurses employed in **acute trusts and in the community**, and how different funding models affect the decision to employ them
- What **evidence is already available** or what new data may need to be gathered to complete the case for the value of the MS Nurse role.

The study involved a review of existing research on MS nurses and on the cost effectiveness of nurses in other specialties, a call for unpublished data from the MS nurse community, interviews with stakeholders and two in-depth case studies of MS nurse teams based in Manchester and in East Kent. This report summarises the results of this work.

In section 1, we outline how **MS nurses currently work**: how many there are, the roles they play, the different models for their employment, and the impact of financial drivers on their activities.

In section 2, we outline **the arguments for employing MS nurses**, and the evidence we found to support these. We describe the theoretical case, present real examples that we identified in our research, and demonstrate through a simple financial model that MS nurses can make savings to the NHS, even using modest assumptions.

In section 3, we consider the **ways that MS nurses can measure their performance** and show their effectiveness. We describe the basic information that MS nurses need to record in order to do this. We consider the role of quality indicators in demonstrating the standards that MS nurses achieve and suggest how these might be developed.

Finally, we draw conclusions about what the MS community needs to do to develop further evidence on the value and impact of MS nurses which can be used to influence the commissioners of the future.

References

[1] See section 1.3 for a more detailed discussion on prevalence of MS.

[2] MS Trust nurses survey, October 2011. The 270 individual nurses represent 235 whole timeequivalents.

[3] RCN 2008 specialist nurse poll reported on RCN website

[4] UK Multiple Sclerosis Specialist Nurses Association (2011). Results of the UKMSSNA job security survey.

1 MS specialist nurse workforce today

In this section, we outline how MS nurses currently work, and changes currently taking place around them which may impact significantly on their roles. We look at:

- The history of the **development of the MS nurse** in the UK
- **MS nurse roles**: similarities and differences between nurse roles;
- **MS nurse caseloads**; and the variable definition of ‘caseload’;
- **Different models of employment**; and how these impact on nurse roles;
- **Different models of funding**; and how these help or hinder MS nursing services.

1.1 Development of the MS nursing workforce

The first three MS specialist nursing posts were established in 1993. With the increasing use of injectable MS drugs in the UK, there was a need to develop MS services and to increase the number of MS specialist nurses. At various points since then, investment has been made to ‘pump prime’ posts in the NHS.

As the number of MS services and specialist nurses grew, it became clear that the scope of the nurses’ role should extend beyond the administration and monitoring of disease modifying therapy. Further investment was made in the professional development of the nurses and the development of services to cover the breadth of need of people with MS at all points in the disease trajectory. The MS Trust, MS Society, Department of Health and the pharmaceutical companies have all played a significant role in the professional and service development of the MS specialist nurse workforce.

Currently there are around 235 whole time equivalent MS specialist nurse posts in the UK.

1.2 MS nurse roles today

Our interviews with MS nurses and consultant neurologists highlighted the wide-ranging role of MS specialist nurses. However, the core functions of MS nurses can be summarised as follows. S/he:

- provides information and education to patients and their carers on how to manage their condition at different stages of the disease from new diagnosis to palliative care;
- provides information and advice to patients on relapse management and the management of MS symptoms such as fatigue, incontinence and cognitive problems;
- initiates and monitors treatment for relapses and other conditions associated with MS (such as urinary tract infections), either as a nurse prescriber or in conjunction with a GP / neurologist;
- provides psychological support to patients, in particular helping them to deal with the uncertainty and stress associated with MS;
- provides information and advice on drug treatments and their side effects; trains patients in self-administering disease modifying therapies (DMTs); administers intravenous (IV) DMTs; and monitors the effectiveness of treatments;
- co-ordinates and brokers care for people with MS from other members of the multi-disciplinary team, such as neuro-rehabilitation and psychological support;
- educates GPs and other health professionals on the management of people with MS;
- recruits patients into clinical research/conducts research that evaluates the effectiveness of treatments and care pathways.

During our interviews, typical comments on the MS nurses’ role included:

> **“The biggest advantage of MS nurses is helping to deal with the uncertainty around MS. Their emotional support is invaluable. My GP is experienced and good but admits to having limited experience of MS.”**
> **Person with MS**

> **“MS nurses are invaluable. They take the pressure off consultant time. They enable patients to be seen quickly. There would be hell to pay if they were taken away.”**
> **Consultant Neurologist**

> **“The MS nurse specialist is a safe pair of hands. I can discharge from hospital to the nurse and she can refer back to me if there is a problem.”**
> **Consultant Neurologist**

A recent comparison[5] of MS nurse roles in different European countries concluded that the MS nurse role in the UK was “perhaps the most advanced in Europe.” This conclusion was based on the view that MS nurses have a greater role in clinical decisions – particularly symptom management and medication management - than in other European countries. MS nurses in the UK can, in principle, manage whole episodes of patient care.

However, we found wide variation in nurses’ service models and levels of clinical autonomy. The consultants we interviewed had different views on the best model for dividing responsibility between consultant and nurse specialist for patient care. Some discharge patients with stable MS to the care of the nurse specialists, while others prefer to keep control and provide at least an annual review for all patients on their books. Most MS nurses run at least some joint clinics with consultants during the week; but one that we spoke to (operating in a rural area without a neurology centre in the patch) operates independently of neurologists and liaises with them only by phone and email. In some areas, patients are able to self-refer to the MS nurse or can be referred directly by their GPs. In others, the MS nurse can only see patients at the instigation of a consultant.

References

[5] Adelphi International Research (2011). European Multiple Sclerosis nurse survey – Key UK findings.

Differences in clinical autonomy also reflect the fact that some MS nurses are qualified prescribers whilst others are not. At one end of the spectrum, some specialist nurses run regular relapse clinics where they can see and assess patients who are potentially suffering a relapse and prescribe and monitor steroid treatment themselves. This was the case in Greater Manchester at the time of our case study visit. At the other end of the spectrum, one MS nurse described how she will suggest appropriate drug treatment for symptom management but send patients to their GP to request it. In between, many MS nurses operate side by side with neurologists and GPs and have to ask them to prescribe medication, which may lead to unnecessary delays. There was general agreement from the neurologists we spoke to that having more MS nurse prescribers would greatly aid the efficiency and effectiveness of the service:

> **"The level of autonomy of the nurse specialist is key. Nurse prescribing is important. She must have the jurisdiction to initiate treatment. Some GPs prescribe steroids for MS patients in inappropriate amounts and/or without proper examination of the patient."**
>
> **Consultant**

In recent years, new therapies for MS have played a part in expanding the MS nursing role. In 2006, natalizumab (Tysabri®) was licensed in the UK for people with rapidly evolving severe relapsing-remitting MS (RES). Natalizumab is given as an IV infusion, in hospital, every four weeks, and patients receiving it must be closely monitored. In many centres, MS specialist nurses run the natalizumab service.

A new oral treatment for MS, fingolimod (Gilenya®) is also likely to have an impact on the role of the MS nurse if it is ultimately approved for NHS use[6]. Fingolimod is an immuno-suppressant drug with potentially serious side effects[7], and patients on it will need more frequent monitoring for blood pressure and white blood cell count, along with eye examinations soon after treatment commences. A small proportion of patients will need referral for cardiology and/or ophthalmology after pre-screening. The extra monitoring required is likely to mean additional MS Nurse clinic time is needed, along with new competencies for the administering of oral therapies.

As we discuss in section 1.4 below, some MS nurses are employed in the acute sector, others in the community. Those nurses who are community based are, in some instances, more focused on progressive MS and patients with complex needs. Some in the acute sector are more focused on newly diagnosed patients and DMTs. But the relationship between employment model and service model is by no means simple.

Recent research has confirmed the breadth of activity associated with the MS nurse role, and some of it concludes that the impact of MS nurses is difficult to demonstrate precisely because of the diversity of roles. In their systematic review, Forbes et al (2003)[8] conclude that there is "insufficient evidence" to show that MS nurses make a difference to patient care. However, they do find for the "appropriateness" of MS nurse roles, reporting a strong association between the reported needs of people with MS and what MS nurses are said to provide. An earlier systematic review by Debroe et al (2001)[9] concluded that the quality of the existing research evidence was too weak to demonstrate the efficacy of the MS nurse role. A more recent literature review by Corry et al (2011)[10] reached similar conclusions, though they did report evidence for and against the value of MS nurses from an analysis of individual studies.

Overall, it is clear that MS nurse roles have evolved differently around the country, based on their personal competencies and preferences and the neurologists they work with, as much as on local needs. Further work is needed to describe and evaluate the different service models in greater detail. And, as we discuss in section 3, demonstrating the value of these roles will be challenging unless services have clear specifications and performance indicators relating to what they are seeking to achieve, and measure their success against these.

1.3 MS nurse caseloads

Our interviews revealed wide variation in the caseloads of MS nurses, varying from 210 in one area to 650 in another, with an average of around 450. A consultant neurologist from one area described how some of his patients were well served by a trio of community-based nurses, while others, living in a different borough, only had access to one acute trust-based nurse.

Difficulties in defining nurse caseload are exacerbated by the fact that there are no reliable data on the number of people with MS in the UK. It is known that the prevalence of MS increases with distance from the equator (north and south), and studies have suggested a prevalence rate of between 100 and 140 per 100,000 in England and Wales, about 170 in Northern Ireland and as high as 190 in Scotland. Individual studies in Orkney have recorded rates of over 200 cases per 100,000. The current best working estimate is 100,000[12], giving a prevalence of around 1 person in every 623 in the UK, but this will significantly over- or under-state true prevalence in individual areas. It is essential, therefore, that a more accurate picture is developed, and a project currently underway at the University of Swansea to develop the UK's first MS Register is a major step forward[13].

We also found variation in what nurses meant by the number in their 'caseload'. In some cases, the number represented only those patients under active management who are reviewed by the MS nurse at least annually. In others, it was based on a patient list but included patients who the nurse might not have seen for some years (and indeed could have died or left the area) but remained on the books in case they returned to the service. Finally, in others, it was a notional figure representing the estimated number of people living with MS in the area served by the MS nurse, based on population.

With these constraints in mind, we undertook further analysis of MS nurse caseloads around the UK by means of a nurse survey in September 2011. Data about the nursing hours available in each location, and the areas covered, were collected from 270 nurses based in 155 NHS Trusts. This data was analysed to create an interactive map of the whole of the UK showing MS nurse coverage. Key findings from the analysis were as follows:

- There is significant variation in nurse availability by Primary Care Organisation (PCO)[14], as shown in Figure 1.1 below, with minutes available per thousand population per week ranging from 2.1 minutes in the least well served PCOs, to 20 minutes in the best served PCOs (excluding outliers). A list of the PCOs within each quintile is given in Appendix D.

References

6 Gilenya was licensed by the UK MHRA in April 2011. Draft guidance published by NICE on 1 December 2011 suggested that Gilenya was not sufficiently cost-effective to warrant funding by the NHS, but this decision is currently out to consultation.

7 MS Trust (2011). Fingolimod – factsheet.

8 Forbes A., While A., Dyson L., Grocott T. & Griffiths P. (2003). Impact of clinical nurse specialists in Multiple Sclerosis – synthesis of the evidence. J Adv Nurs 42(5), 442-62.

9 Debroe S., Christopher F. & Waugh N. (2001). The role of specialist nurses in multiple sclerosis: a rapid and systematic review. Health Technology Assessment 5, 1-47.

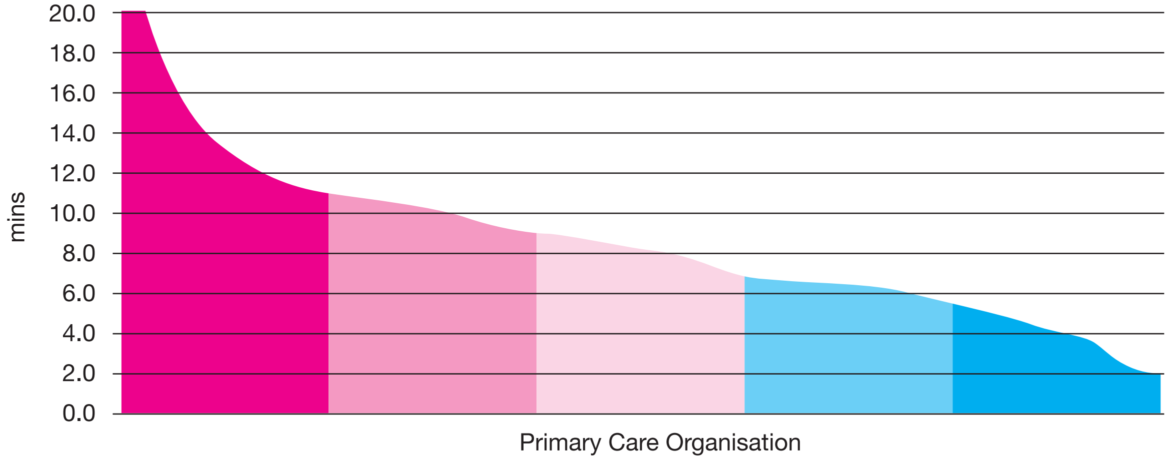
10 Corry M., McKenna M. & Duggan M. (2011). The role of the clinical nurse specialist in MS: a literature review. British Journal of Nursing 20(2), 86-93.

12 For a further discussion of the available estimates, and references, see http://www.mstrust.org.uk/atoz/prevalence_incidence.jsp

13 See www.ukmsregister.org

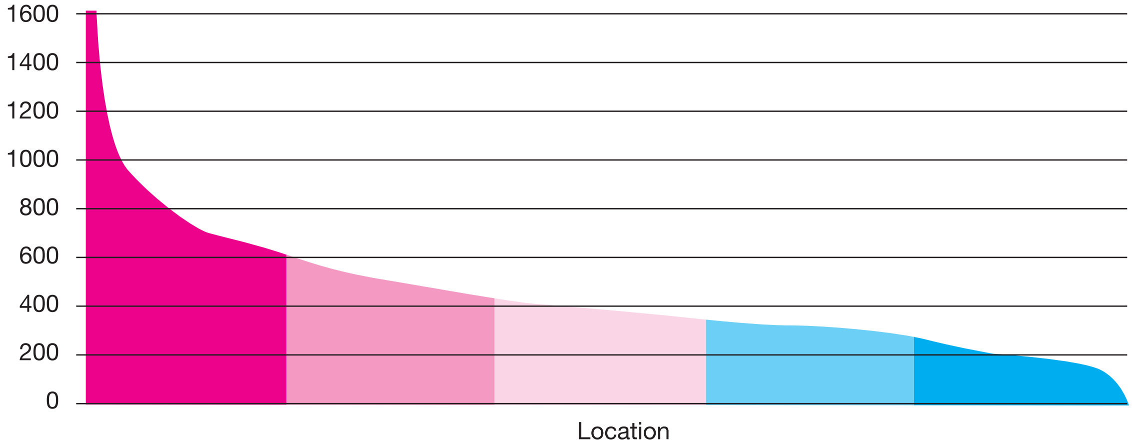
14 PCO (Primary Care Organisation): PCT in England, Health Board in Scotland, Local Health Board in Wales and Health and Social Care Board in Northern Ireland.

Figure 1.1 Available nurse minutes per week per 1000 population by Primary Care Organisation



- There is also great variation in caseloads by nurse location, as shown in Figure 1.2, which shows the estimated number of people covered by each whole time equivalent (WTE) nurse, based on a prevalence estimate of 1 person in every 623 having MS (which is unreliable for the reasons discussed above). In some locations each nurse covers only an estimated 150 people with MS, whilst in the most stretched locations, one WTE nurse covers over 1500 patients.

Figure 1.2 Estimated number of patients covered per WTE MS nurse, by MS nurse location



- There is also significant variation in the average distance to the nearest MS nurse by PCO and by nurse location, as shown in Figures 1.3 and 1.4. Although it is obvious that a patient in the Highlands of Scotland is likely to have to travel further to find an MS nurse than someone in a large city, the variation cannot be entirely explained by this urban-rural split. For example, the nurse based at St James' Hospital, Portmouth serves patients on average living only 5km away, whereas the nurse based at Calderdale Royal Hospital in Halifax serves patients on average 40km away.

Figure 1.3 Average travel distance from patients to nearest MS specialist nurse, by PCO

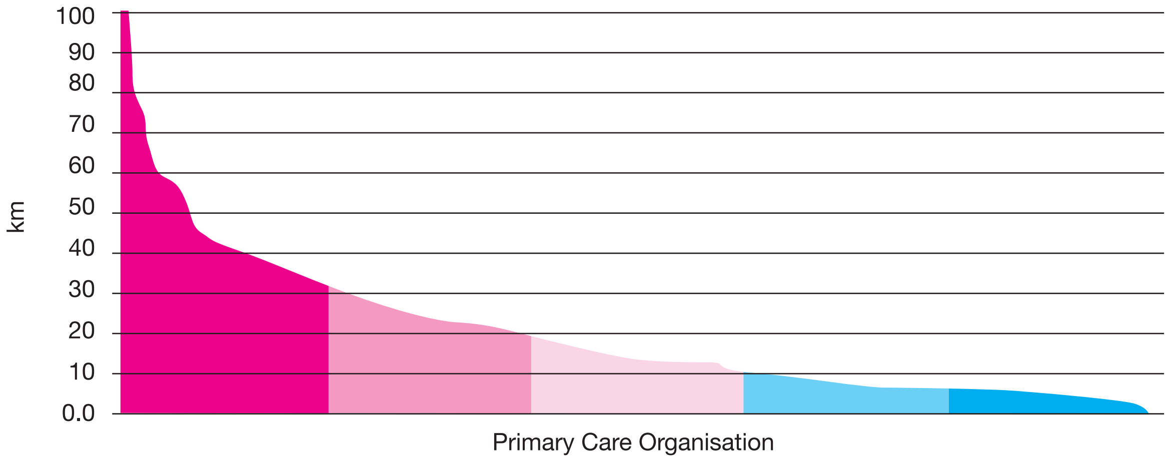
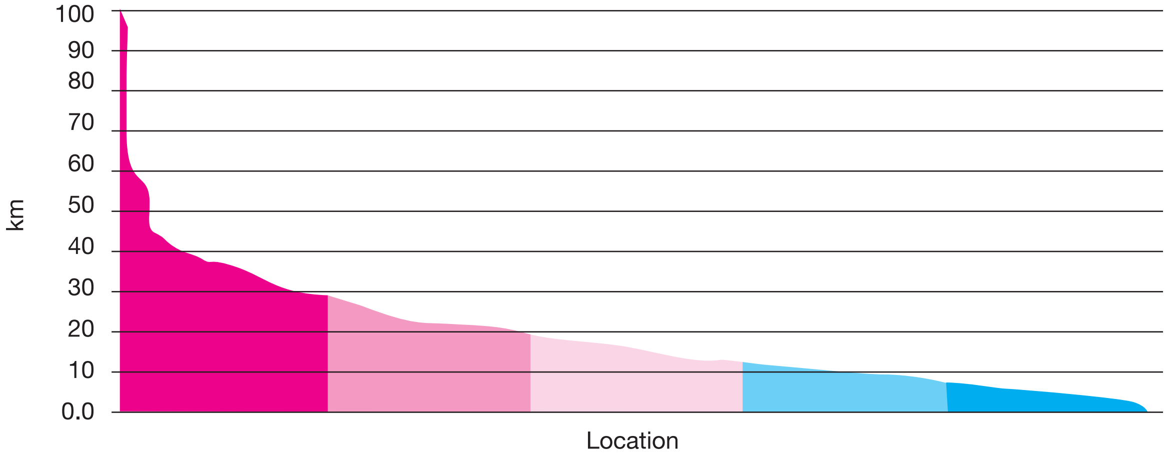


Figure 1.4 Average travel distance from patients to nearest MS specialist nurse, by MS nurse location



Interviewees discussed the wide variation in the needs of people with MS depending on the stage and rate of progression of their disease. However, there was a lack of consensus on how much input should be offered by an MS nurse to different types of patients, other than for newly diagnosed patients, those on DMTs and those experiencing relapse, where clear protocols usually exist. A number of nurses we interviewed expressed concern that the level of support they gave to patients not in those categories was extremely dependent on how vocal those patients (or their relatives) were in seeking help, and that there was a real risk that other patients 'on the books' had significant unmet needs but were not being seen regularly.

There is a need for an agreed definition of caseload and more clarity about what size of caseload can be served by an MS nurse to an acceptable standard. The MS Trust is currently undertaking further work to quantify this. In the meantime, the map of MS nurse coverage is being used to highlight locations which are least well served by nurses, and Trusts where nurses are particularly stretched.

1.4 Different models of employment

A recent survey by the MS Trust found that three out of four MS nurses were employed by acute trusts, with the remainder employed by community providers.[15] Two thirds of the MS nurses that we interviewed were employed by acute trusts, the rest in the community.

Many MS nurses have lived through significant and repeated organisational change in recent years. Some acute neurology services have been reorganised to create larger neurosciences centres serving wider geographic areas on a hub-and-spoke model. In some areas, such as Manchester, this has led to the creation of larger MS nurse teams covering a wider area. Those employed in the community have also seen significant changes to their employment models as a result of the Transforming Community Services agenda, which required PCTs to separate their commissioner and provider functions by March 2011. PCTs have chosen to do this in different ways. In some cases community health services have become semi-independent social enterprises. Others have integrated with a mental health trust, or vertically integrated with an acute trust. For example, the MS nurse for Central Surrey is now employed by Central Surrey Health, an employee-owned social enterprise within the NHS. She is part of a co-located neuro-rehabilitation team which also includes a Parkinson’s Disease specialist nurse, physiotherapists, occupational therapists, speech and language therapists, psychologist, case management, a dietician, and administrative support. The four MS nurses based at Dulwich Community Hospital in South East London have recently become part of the new ‘community directorate’ of Guys and St Thomas’ NHS Foundation Trust.

In the interviews, nurses strongly defended their own employment model and cited specific advantages of each, specifically:

Perceived advantages of being employed by an acute trust	**Perceived advantages of being employed by a community provider**
Closer working with, and easier access to neurologists (Usually) possibility of working in a team with more than one MS nurse, allowing for peer review, sharing of good practice, and cross cover Greater opportunities for professional development and participation in research through being in a neurology centre Ability to pick up MS patients in A&E and on wards, and to facilitate discharge.	Closer links to GPs Ease of establishing clinics in the community, closer to patients’ homes Possibility of integrating with community rehabilitation services Sense that MS nursing is more closely aligned with community services than acute (with focus on keeping patients out of hospital and helping them to self-manage)

Regardless of the employing organisation, the MS nurse role has evolved considerably over the last decade. There are more telephone consultations and community clinics based in locations such as health centres, community hospitals and MS Therapy Centres, and it is clear that this will continue:

References

[15] MS Trust (2010). Survey of MS nurses

“Acute trust clinics are hardly needed. They are only for new patients to confirm diagnosis and to start therapies. Primary progressive and secondary progressive patients are only seen in hospital if there is a new problem.”

MS nurse

“GP commissioners will be asking for much more local targeted care. They will want consultants out of their “ivory tower” and into health centres. They will want care delivered more cheaply by a MS nurse than a consultant.”

Consultant Neurologist

At the same time, though, it is important that nurses do not become disconnected from other specialist neurology services:

“The issue is having a co-ordinated approach. The nurse and consultant should ideally be co-located. It helps with communication and education. The patient feels the benefit of a more coordinated approach. It’s particularly important for standards of care, such as imparting the initial diagnosis.”

Consultant Neurologist

Our conclusion is that both models of employment have advantages and drawbacks: the challenge is to set up posts which capture as many advantages of both as possible.

1.5 Different models of funding

Funding models can have an important influence on the way MS nurses work and the ease with which they can fulfill their role. In the acute sector, we found two funding models in operation. Under **Payment by Results**, a tariff (price) is agreed between the acute provider and the PCT for different categories of activity, and the PCT is billed on a cost per consultation basis. As neurology outpatients does not yet fall under the national tariff system, prices are subject to local agreement. Under **Block Contracts**, the PCT pays the provider a lump sum to cover the MS nursing service, ideally against an agreed specification (though in many cases these have not been developed). All community provider activity is funded under block contracts.

A clear benefit of the PBR system is that in principle, it means that more MS nurse activity can generate additional income for the Trust and this can fund the expansion of the service. Some nurses we spoke to were strong advocates of PBR for this reason. However, we found in practice that PBR is often problematic for nurses and does not align well with what they are seeking to achieve, for example:

- Some acute Trusts charge for MS nurse activity as a ‘neurologist follow up appointment’, but in order to justify this, the nurse must be sitting in a consultant-led clinic to deliver the service. This can make it hard for nurses to establish nurse-led and/or community based services.
- Some commissioners have capped the ratio of follow up to new appointments that they are prepared to pay for. This can mean that nurse activity cannot be charged for if billed as a ‘neurologist follow up appointment’. One nurse said that, in her trust, she must discharge patients after one appointment, and they have to be re-referred by their GPs for a subsequent appointment in order to comply with new to follow up limits.
- Some acute trusts require clinicians to discharge patients if they do not attend (DNA). In one acute trust, the MS nurse has successfully argued that this is not fair on patients with MS who may have cognitive problems.
- Telephone consultations and patient education sessions (such as courses for people newly diagnosed with MS) are not usually chargeable under PBR and are therefore not recognised or rewarded, even though they offer immense value to patients and can save the NHS money.
- Where clinics are held outside the hospital, it can be hard for the Trust to capture the activity data and associated revenue. This can create artificial barriers to setting up community based services.

In general, MS nurse services funded under a block contract appeared to have greater flexibility than nurses funded by PBR to respond to patient need (for example offering longer appointments and more community based clinics) and move activity out of the acute sector into the community. However, under block contract arrangements it is essential that the service is tightly specified and quantified, or otherwise the ‘block’ will hide how much work MS nurses are carrying out.

The case studies

Greater Manchester MS nurse service

The Greater Manchester MS nurse services operates a “hub and spoke” model. There is a centrally-located disease modifying service for MS patients based at Salford Royal NHS Foundation Trust. The model is of “shared care” for patients on disease modifying drugs. There are 7 specialist nurses (6.3 WTE), all employed by Salford Royal and coordinated by a nurse consultant. Each area of the city is covered by one or more nurses, and they spend much of their time working in the community within their ‘patch’. The nurses work alongside a team of consultant neurologists who split their time between Salford Royal and other hospitals across Greater Manchester.

East Kent Hospitals MS nurse service

East Kent is also an example of a “hub and spoke” model for specialist nurses. There are three MS nurses based at Kent and Canterbury Hospital covering the East Kent area with a caseload of more than 2,000 patients. They work closely with a consultant neurologist who has a special interest in MS. They are funded through a block contract with the PCT for neuro-rehab services. In 2012 this will change to funding by PBR.

This section has considered the roles MS nurses play, the variable caseloads of nurses around the UK, the different models for their employment, and the impact of financial drivers on their activities. In the next section, we look at the economics of MS nurse roles.

2. The economic value of MS nurses

In this section, we outline the case for the economic value of MS nurses. We present the evidence that we collected in the course of our research, and the conclusions that we have drawn. We set out:

- an **overview of the data**;
- **how MS nurses achieve savings to the health economy**;
- **evidence of the cost-effectiveness of MS nurses**;
- examples from **other specialities** which employ clinical nurse specialists;
- **what savings MS nurses could achieve**: our own analysis of the type and level of cost savings that could be realised;
- what MS nurses can do to **show their value**: how MS nurses could record and analyse data which shows their economic impact; and
- **how MS nurses can improve productivity**.

2.1 Overview of the data

During our research, we searched extensively for evidence of the economic value of MS specialist nurses. We looked for academic papers, policy documents and local research. We asked the MS nurses whom we interviewed for any relevant material. Through the UKMSSNA, we asked MS nurses to provide us with examples of business cases and service specifications. This enquiry generated only three responses. In total, we found some national documents and four business cases prepared by MS nurses.

Put together, these research papers and economic arguments begin to build up a picture of the financial benefits MS nurses bring to the NHS. However, we were struck by the general lack of economic data. Firstly, most of the papers we found articulated the economic arguments for MS nurses clearly but these were usually theoretical and were not backed up with hard data. Secondly, since the study by Johnson et al (2001), which showed a cost benefit of MS nurses from a reduction in unplanned hospital admissions, there have been no academic studies on the economic impact of MS nurses (although there have been published studies on patient satisfaction and improved patient outcomes[16]). This compares unfavourably with rheumatology and cancer, for example, where peer-reviewed economic research on nursing roles has recently been published (see Appendix G for a summary), and Parkinson's disease, where specialist nursing posts pump-primed by the Parkinson's Disease Society (now Parkinson's UK) were rigorously evaluated for their first two years of operation.

Furthermore, there is little data available at a local level. Few MS nurses have tried to analyse the cost-effectiveness of their posts. A surprising number do not even keep logs of basic activity, such as the number of patients seen and clinics run. In addition, the quality of evidence is often weak - barely more than 'back of the envelope' calculations.

References

[16] Forbes A., While A., Dyson L., Grocott T. & Griffiths P. (2003). Impact of clinical nurse specialists in Multiple Sclerosis – synthesis of the evidence. J Adv Nurs 42(5), 442-62.

2.2 How MS nurses achieve savings to the health economy

In today's economic environment, commissioners will not only want to know that services are cost effective, but that they generate cash-releasing savings before agreeing to fund a new MS post. Similarly, if posts are under threat, demonstrating that cash costs to commissioners would actually increase if the service was withdrawn creates a powerful argument for retaining specialist nurses.

> **"The most important factor in employing more nurse specialists, is where else in the system is there money to do that? It's also about quality standards: is this the right clinical thing to do? MS nurses have to be at least financially neutral."**
> **PCT commissioner**

The theoretical arguments and anecdotal evidence for the economic value of MS nurses are strong. However, who benefits from these savings varies considerably. MS nurses can, in principle, achieve the following cost savings through the mechanisms shown in figure 2.1 (opposite).

During our research we found other economic arguments which had been made to support the employment of MS nurses. However, these may be examples of costs being shifted around the health system rather than true economic benefits. For example:

- Home visits and community clinics may appear cheaper than appointments in secondary or tertiary care, but this may be simply a feature of the way that facilities are charged for. There are 'hidden' costs associated with home visits – such as nurse travel time - which may not be accounted for.
- Nurse-led clinics can sometimes be re-coded as neurology appointments where the nurse sits in a neurology clinic, generating additional income for an acute trust if neurology is funded by PBR rather than a block contract. This is an example of cost shifting from the provider to the commissioner.

2.3 Evidence of the cost-effectiveness of MS nurses in practice

Two MS nurses shared with us analyses of the cost savings achieved by their service. These analyses focus on reductions in emergency admissions, freeing up consultant appointments in an acute outpatient setting, and freeing up appointments with GPs. These examples indicate the type of savings that can be achieved by MS nurses.

The case study

Central Surrey Health

Central Surrey Health have estimated that their MS nurse (Liz Wilkinson) achieves significant cost savings to the PCT by reducing consultant neurology appointments and non-elective admissions. Estimates for 2010 were:

- avoided admissions – 28 patients at the national tariff of £3039 per non-elective admission achieving a total saving of £85,000;
- reduction in consultant follow ups – 271 appointments avoided achieving a total saving of £28,000.

They also estimated that she helped avoid 32 tertiary referrals for DMTs.

Source: Adapted from material provided by Sally Bonynge, Executive Lead for Long Term Care, Central Surrey Health

Figure 2.1: How MS nurses can achieve cost savings and for whom

Cost savings	Achieved through MS nurses…	Who benefits economically	Cash releasing for commissioners?
Reduction in GP consultations	Providing rapid access telephone or face to face consultations on problems needing a rapid response, such as continence issues, UTIs, medication side effects, possible relapses or other health problems where the patient is uncertain whether they are linked to their MS.Educating patients and their carers: giving information and advice which promotes self-management and reduces psychological distress.Educating GPs and other primary care health professionals so that they are able to offer more effective care and reduce the need for follow up appointments.	GP practices	No
Reduction in A&E attendances	As above	PCT/Clinical Commissioning Group (CCG) Acute Trust (where differential tariff applies)[17]	Yes
Reductions in neurology consultant appointments (or freed up time to see more patients and reduce waiting times)	Providing routine follow up consultations for all patients following diagnosis and where the patient's MS is stable. Providing relapse clinics and relapse management (in some cases prescribing steroid therapy). Undertaking routine medication monitoring including regular testing and side effect management.	PCT/CCG	Yes but only if there is no backlog of neurology referrals, otherwise result will be reduced waiting times
More effective use of disease-modifying drugs: more appropriate prescribing, increased adherence and reduced side effects	Providing information and promoting shared decision making at the point of prescription, both of which will lead to patients making more informed decisions and promote adherence.Training patients in self-injecting and managing their medications, again promoting adherence.Monitoring and altering medication appropriately (and recommending cessation of treatment if it is not benefiting the patient).	PCT/CCG: if the net result is reduced prescribing: otherwise this is a health gain rather than a cost saving.	Possibly
Reductions in emergency admissions	Responding to patients with symptoms of relapse or other crises before they present to A&E.Offering home-based steroid treatment for relapses;Seeing patients in A&E and working out a care plan to prevent admission.Co-ordinating multi-disciplinary care: ensuring patients have access to neuro-rehab, psychological support and specialist help and thereby reducing the likelihood of crisis.	PCT/CCG	Yes
Reduced length of stay in hospital	Visiting patients on wards and facilitating early discharge.	Acute Trust	No
Reduced hospital readmissions	Leading on discharge planning to ensure that discharge is well supported with any services necessary.	PCT/CCG	Yes

References

17 In some areas, acute trusts are penalized with a reduced tariff if A&E attendances go above a threshold limit.

The case study

Northamptonshire Healthcare NHS Trust

Financial savings

The MS specialist nurse for Northamptonshire Healthcare NHS Trust, who covers the north of Northamptonshire, has developed a care pathway for people with MS to prevent unnecessary hospital admissions through A&E and the out of hours GP service. She has been monitoring admissions avoided since September 2007 by counting MS patients having relapses who would have been admitted, had it not been for her intervention. She estimates that within one year she has saved the NHS £66,000 through 34 admissions avoided.

	Emergency admission IV methylprednisolone	Home treatment oral methylprednisolone	Cost saving
Cost per case	£1,995	£61.65	£1933.35
Total cost for 34 episodes	£67,830	£2,096.10	£65,733.90

She also estimates that she saved £16,402 by freeing up 165 consultant neurology appointments. The nurse estimates that the nurse service offers a net saving to her trust of £13,532 after salary and on-costs have been taken into account. The MS nurse estimates that in one year 61 people with MS have been treated within their own home for infections, stress and other problems, rather than being admitted to secondary care. This is in addition to the 34 relapse admissions avoided that are set out in the table above.

Patient examples to support her case

Prior to new care pathway

In the summer of 2007, a woman with MS who presented to A and E with an exacerbation of her MS symptoms, vomiting and a headache. She was admitted to an acute ward for treatment with IV methylprednisolone. Her symptoms abated within four hours but she remained in hospital for three days. After discharge, it appeared that the woman had been suffering from sunstroke. If the MS specialist nurse had been able to review the woman, the admission would have been avoided as well as the unnecessary treatment with steroids.

After new care pathway

After new care pathway: In November 2009, a woman visited her GP with the symptoms of an MS relapse. The GP contacted the MS specialist nurse who made suggestions for her treatment. The GP prescribed the recommended medication and the specialist nurse reviewed the patient at home the following day. Within ten days the woman had fully recovered without the need to be admitted to hospital.

Source: Adapted from 2009 case study provided by Debbie Quinn, MS nurse specialist

MS nurses should continue to publicise examples of their cost-effectiveness. In order to be robust, these examples should:

- use transparent and evidence-based assumptions. Calculations of ‘admissions avoided’ is subjective unless there is data for comparing admission rates before and after an MS nurse comes into post. Obtaining this data is often difficult given that patients with MS can be admitted under numerous diagnoses codes. Where MS nurses record this information – using, for example, the UKMSSNA pro forma developed for this purpose – the evidence is more robust.
- take account of all the costs of employing the MS nurse, including on costs, office costs and clinic rooms. Income generated or savings made must be net of those costs.
- avoid using arguments based simply on shifting costs between different parts of the health system.
- be tailored to the perspective of the audience, for example either an acute trust employer or clinical commissioning group, and the funding system which is in existence.
- be based on locally relevant cost information. National tariffs can be used for many calculations but many costs are locally determined. For example, the average cost of a GP consultation is locally derived and varies from area to area.

2.4 Evidence from other specialties

We looked for evidence from other specialities on the value of employing clinical nurse specialists in order to see whether methods used elsewhere could be utilised to measure the financial value of MS nurses.

There has been a flurry of recent reports seeking to demonstrate the vital role of clinical nurse specialists working in different specialities. They include Quality in Nursing. Excellence in Cancer Care: the Contribution of the Clinical Nurse Specialist (NHS/Macmillan 2010) and the RCN’s booklet Specialist Nurses. Changing Lives, Saving Money (RCN 2010). They also include evidence from nurses working in cardiology, rheumatology and Parkinson’s disease.

In Appendix G, we summarise five reports from other specialities. While there are strengths and weaknesses in the methodologies used, we consider these reports relatively robust and relevant to the debate about the economic role of MS nurses.

2.5 What would an economic model for an MS nurse service look like?

As we did not find many economic analyses of MS nurse posts, we built a small model to illustrate the savings that an MS nurse could make. We show that a new MS nurse post could yield a net cash releasing saving to commissioners of £54,000 if s/he could save 300 outpatient appointments and 40 emergency admissions. To be sure of just breaking even, one MS nurse would only need to save 199 outpatient appointments and 21 emergency admissions. Our analysis is set out in the table below. Costs avoided are based on the MS Society cost calculator (2011 edition) – see Appendix E for more information.

Figure 2.2 Illustrative costs and savings associated with a new MS post

£		Assumptions
Costs		
Salary	35,000	Band 7 mid-point
On-costs	5,950	17% of salary
Telephone	480	£40 per month
Mileage	791	40 miles per week, 46 weeks per year
Computer	500	
Clinic receptionist (shared)	5,888	4 clinics per week, £36 per clinic
Clinic room cost	7,360	4 clinics per week, £40 per clinic
Secretarial support	8,011	
TOTAL COST	63,980	

Potential cash releasing savings (illustrative)

	Number saved	Cost each	Total saving
Neurology follow up outpatient appointments	300	£91	£27,300
Neurology emergency admissions	30	£2,331	£69,930
Other emergency admissions (e.g. UTI)	10	£2,056	£20,560
TOTAL SAVING			**£117,790**
NET CASH RELEASING SAVING TO COMMISSIONER			**£53,810**

Breakeven assumptions

	Number saved	Cost each	Total saving
Neurology follow up outpatient appointments	199	£91	£18,109
Neurology emergency admissions	10	£2,331	£23,310
Other emergency admissions (e.g. UTI)	11	£2,056	£22,616
TOTAL SAVING			**£64,035**

2.6 What can nurses do to show their value?

A major difficulty for MS nurses in presenting their economic value is that many of them do not have basic information on activity levels and costs. The majority of MS nurses we interviewed did not have information that could inform a cost benefit analysis. It is clearly important that nurses begin to keep records and make calculations that can be used to show their economic value to employers and commissioners. The areas that will be useful to clinical commissioners and employers are those outlined in figure 2.1 above. Tools already exist to help collect and analyse economic data on MS nursing and other neurological services, and these are described in Appendix E.

To date, information that has been collected by MS nurses has tended to be around savings to the acute sector. This data will continue to be important for MS nurses employed by acute trusts. However, a more powerful argument for clinical commissioning groups is likely to be around reducing workload in primary care – for example freeing up GP appointments. Reducing non-elective admissions will also be important for the cost savings it will generate.

This suggests that MS nurses should keep records based on asking their patients “what would you have done if you had not contacted/been seen by the MS specialist nurse?” It will also mean MS nurses or their clinical managers identifying the costs of alternatives – from national tariff data or locally derived information obtainable from the PCT/CCG.

2.7 Improving productivity

MS nurses are a skilled and scarce resource. It is therefore essential that they use their time efficiently, both to maximise the cost-effectiveness of their service but also to ensure that they can manage the caseload relatively comfortably and give patients who need it rapid access to care.

From our interviews and case study visits, we identified several examples of MS nurses introducing efficient working methods. These included:

- a protocol for home visits developed (Greater Manchester MS nurse service);
- a care pathway developed in partnership with the local acute hospital and GPs to prevent unnecessary hospital admissions (Northamptonshire MS nurse service);
- patient group education programmes to give an overview of MS to newly diagnosed patients (Greater Manchester MS nurse service)[18], or to help patients and their carers develop self-reliance in specific areas such as fatigue management, cognition and spasticity (East Kent MS nurse service);
- MS nurses discharging patients who are able to self-manage their MS with contact details of the MS specialist nurse service.

However, we also found examples of potential inefficiency:

- joint clinics, where all patients are seen routinely by both an MS nurse and a consultant neurologists, whether or not this is needed, creating unnecessary duplication;
- unnecessary use of home visits: although we found broad consensus that home visits are very beneficial at diagnosis, and for some patients with mobility and cognitive impairment, they are costly to deliver (one home visit typically takes four times the time of a clinic appointment when nurse travel time is factored in). Therefore offering home visits where there is no clear rationale, or simply because there is no available appointment in a clinic, is a major drain on productivity;
- where home visits are used, a lack of systems to schedule visits to minimise travel times. Such systems are becoming commonplace in community providers, but where MS nurses are operating in the community but employed in acute Trusts, they are much less likely to have access to them.
- MS nurses not being accredited prescribers needing to send patients to their GP to obtain a prescription for a medicine which the nurse had recommended – therefore not saving a GP appointment. (Non-prescribing MS nurses can avoid this if they work alongside a neurology team or GP team and can ask for a prescription to be signed without the patients needing to make a separate appointment).
- lack of systems for ensuring that MS nurses are made aware of patients with MS admitted to hospital.
- lack of information tools to assist in recalling and prioritising patients. Some MS nurse teams still rely on card index systems, which make it difficult to ensure that patients in the caseload are seen proactively according to need, and more likely that support will be based on how demanding individual patients are.

- lack of IT infrastructure: sometimes 2-3 MS nurses sharing a single computer. We observed virtually no use of mobile IT, which could assist in recording activity taking place outside the hospital setting. A reason for this may be that acute Trusts are not experienced in managing nurses operating in the community or providing tools to assist them.
- considerable variation in caseloads and in the number of patients actively seen.

It is clear that MS nurses would benefit from examining their productivity and sharing examples of efficient working practices.

2.8 Conclusion

Producing more evidence-based information on the savings which can be generated by MS nurses will help justify MS nurse posts at a time of economic austerity. It will help build up a case that can be put to clinical managers and commissioners for retaining and expanding MS nurse services. But beyond just measuring cost effectiveness, MS nurses need to evaluate the performance and quality of their services. We explore what this means in the next section.

3 Measuring nurse performance

In this section, we consider other ways that MS nurses can measure their performance and show their effectiveness. We describe the basic information that MS nurses need to record in order to do this, and we discuss the role of quality indicators. We cover:

- logging activity: the basic information that MS nurses need to monitor their impact;
- setting standards: why performance indicators are important, some examples of what these might look like for an MS nurse service, and their relationship to the new NHS Outcomes Framework;
- auditing performance: completing the audit cycle by monitoring performance against standards, making service improvements and tracking the results; and
- measuring patient experience: methods for finding out what patients really think of the MS service, and how their experience can be improved.

Delivering cost-savings for the NHS is of course not the reason why MS nurse posts were established. MS specialist nurses were appointed to improve the care of people with MS. We found a consensus among healthcare professionals and patients that MS nurses had transformed the care of people with MS, particularly in offering emotional support, co-ordination of care, rapid access to specialist services, and information about the condition.

> **“MS nurses have completely changed care for people with MS. In the early1980s, you would be seen every six months by a neurologist. There were endless waits, and you couldn’t be seen by anyone in the meantime if there was a problem. MS nurses live it day by day with patients.”**
>
> **Person with MS**

References

18 It should be noted that the provision of ‘newly diagnosed’ courses is controversial: not all nurses we interviewed thought that these were appreciated by patients, and some thought they could generate additional anxiety.

The role of MS nurses is diverse. It covers a wide range of activities, the most commonly cited being psychosocial support, co-ordination of care, onward referral, and the provision of specialist advice[19]. Measurement of outcomes in these areas would strengthen the case for the MS nurse specialist role by showing commissioners the added value the nurse brings to patient care. However, we found that empirical evidence for how MS nurses improve patient care is weak[20]. MS nurses need to have hard evidence to counter the view that their achievements are “aspirational” and “anecdotal” rather than objectively shown[21].

In this section, we suggest four key activities that MS nurses can use to collect this evidence: logging activity, setting standards, undertaking clinical audit and measuring the experience of their patients.

3.1 Logging activity

Before MS nurses can begin to measure their performance they need to log their activity. We found that a surprisingly high number of MS nurse services appear not to do this. High caseloads, difficulties in accessing computers, and paper-held patient records are all understandable reasons why MS nurses may not keep records of their activity. In addition, many commissioners have not required it. However, it is extremely important that all MS nurses have information to present to CCGs.

At a minimum, MS nurses should keep records of the following by month:

Caseload information	number of patients on their books, by type and stage of MS number of these patients seen within the past year number of patients on DMTs number of new referrals received and discharges / deaths
Activity information	number of clinics held, with locations number of new and follow up consultations at clinics number of home visits undertaken (with reason) number of dnas at each clinic number and length of telephone consultations undertaken other activity, e.g. attendance at care planning or discharge meetings about specific patients time spent on non-clinical activities such as admin
Unmet need	waiting time for a nurse appointment number of referrals or requests for consultations which could not be handled

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References

19 Forbes A, While A, Dyson L, Grocott T, Griffiths P. Impact of Clinical nurse specialists in multiple sclerosis – synthesis of the evidence. Journal of Advanced Nursing, 42(5), 442-462

20 De Broe S, Christopher F, Waugh N (2001) The role of specialist nurses in multiple sclerosis: a rapid and systematic review. Health Technology Assessment 5, 1-47.

21 Nolan M. & Nolan J. (1997). Rehabilitation in multiple sclerosis: the potential nursing contribution. British Journal of Nursing 6, 1292-1309.

Electronic databases already exist to help nurses log activity. The ideal system should not only record activity but also provide a recall system and clinical record system. Some databases have been developed by MS nurse services themselves, others by commercial companies.

3.2 Setting performance standards

All NHS organisations are expected to have standards of care for their work. Standards are important for demonstrating clinical effectiveness, patient safety, patient satisfaction as well as showing how a service is accountable and committed to continuous improvement. The coalition government has already indicated that they expect a greater emphasis than previously on quality of care, and that this will be measured by clinical outcomes, patient safety and patient experience. MS specialist nurses should also set standards for their work to demonstrate how they improve care for people with MS. Standards are essential for measurement of outcome and demonstration of the added value of the MS nurse role.

There are currently no national quality standards for MS nursing, although the MSSNA has recently produced an online audit tool with a number of standards in it. MS nurse services that have developed local quality indicators have done so in different ways. We found some that were drawn up as part of a business case. Others had been written into service specifications. A few had been developed via the trust's clinical governance arrangements. The best examples we found were evidence-based and were mapped against the 11 Quality Requirements identified in the National Service Framework (NSF) for Long-term (Neurological) Conditions (2005)[22] and/or the NICE Clinical Guideline on MS[23]. The latter is the route recently taken by the MS Neurology Sub-Group on Clinical Governance at Salford Royal Hospital. Salford has derived quality indicators from the priorities within the NICE Guideline that they consider are within the control of the MS nurse service. The NICE Guideline is scheduled to begin revision later in 2012, which may mean that quality indicators based on the Guideline will need amendment.

A different approach to the development of quality indicators is to mirror the set of goals outlined in the recently published NHS Outcomes Framework. The MS nurse service at Kent & Canterbury has begun to map their standards against this. The Outcomes Framework is an important document which NHS organisations have been told to "take heed of" as an indication of the direction of travel for the NHS. The Framework consists of a small set of outcome goals known as "domains." Under these sit overarching indicators and a small set of improvement areas. The Framework indicates how these improvement areas should be measured. An example is given in figure 3.1 opposite. This shows Domain 2 which is concerned with the management of patients with long term conditions.

In the future, each domain will be supported by a suite of NICE Quality Standards which will define what high quality care looks like for a particular pathway of care. For the time being, the Outcomes Framework is only indicative but since the Government has signaled that it will be important for clinical commissioning, it would seem sensible for MS nurses to take the outcomes into account as they develop their own quality indicators.

References

[22] Department of Health (2005). The National Service Framework for long term conditions.

[23] NICE (2004). Clinical guideline 8. Management of Multiple Sclerosis in primary and secondary Care.

Figure 3.1: Domain 2 of the NHS Outcomes Framework

Domain 2

Enhancing quality of life for people with long-term conditions

Overarching indicator

2. Health-related quality of life for people with long-term conditions (EQ-5D)

Improvement areas

Ensuring people feel supported to manage their condition

2.1 Proportion of people feeling supported to manage their condition.

Improving functional ability in people with long-term conditions

2.2 Employment of people with long-term conditions

Reducing time spent in hospital by people with long-term conditions.

2.3.1 Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)
2.3.2 Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s.

Enhancing quality of life for carers

2.4 Health-related quality of life for carers (EQ-5D)

Enhancing quality of life for people with mental illness

2.5 Employment of people with mental illness.

There are two other quality programmes, developed by the Department of Health, that MS nurses can also draw on in developing quality indicators. The first is the Commissioning for Quality and Innovation (CQUIN) payment framework which enables commissioners to reward quality. It links a proportion of providers' income to the achievement of local improvement goals. However, CQUINs are limited to one scheme per provider and the financial value of CQUIN schemes is small. MS nurses should talk to their trust to find out which CQUINS their provider has signed up to.

Secondly, MS nurses can refer to local plans for QIPP – the Quality Innovation Productivity Prevention programme – in building their own set of quality indicators. QIPP aims to improve quality of care and achieve efficiency savings. There is a national workstream for long term conditions, supported by a national website with guidance documents and case studies[24].

Based on the information that we received from MS nurses, we have drawn up some examples of quality indicators. These are not intended to be comprehensive, and our recommendation would be that, as a matter of priority, a set of SMART[25] quality indicators should be developed for MS nursing services based around the NHS Outcomes Framework and taking into account NICE guidance and the National Service Framework on long term (neurological) conditions (acknowledging that these are both, in some areas, out of date).

References

[24] See http://www.dh.gov.uk/en/Healthcare/Longtermconditions/index.htm
[25] Specific, Measurable, Achievable, Relevant, Time-bounded

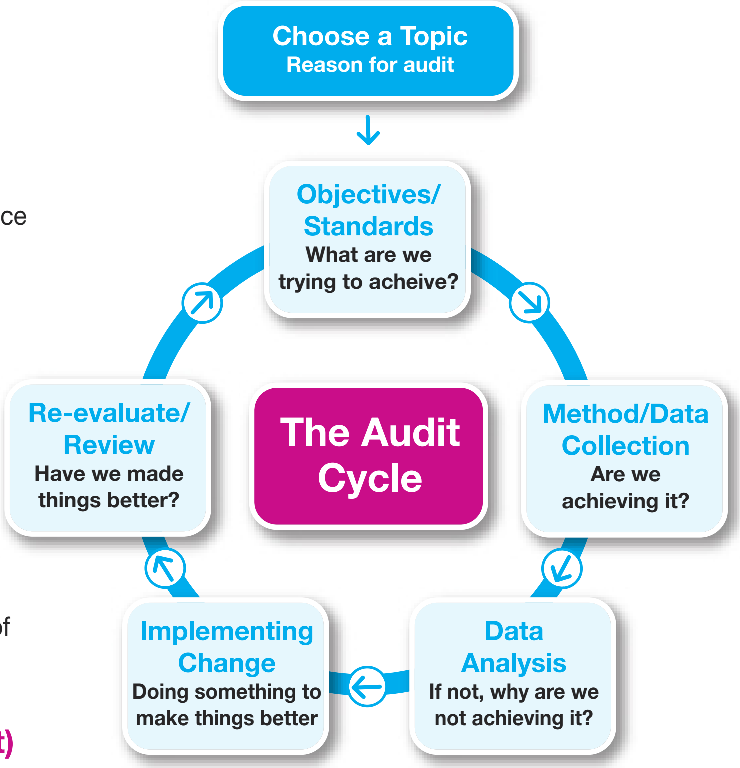
Figure 3.2: Examples of potential quality indicators for MS nurses

Subject	Sample quality indicators
New diagnosis	All patients newly diagnosed with MS are contacted within 3 working days of receiving referral. All newly diagnosed patients offered a home visit appointment within 2 weeks of receiving referral. All newly diagnosed patients offered opportunity to attend an education course within 3 months of diagnosis
Relapsing patients	Patient contacted within 24 hours of receiving referral from GP/ neurologist or call from patient who is relapsing, has worsening symptoms or is in crisis will have their call returned with 1 working day Assessment for steroid treatment undertaken within 1 week and treatment initiated within 24 hours
Patients with progressive MS	All patients have a named care co-ordinator (MS nurse, community matron, case manager etc) and a comprehensive personalised care plan which has had input from the specialist MS nurse during the past year
Annual review	All people with MS are offered an annual review with the MS nurse.[26]
In patients	All patients with MS with an unscheduled admission to hospital are seen on the ward by a MS nurse within 3 days of admission

3.3 Auditing services against standards

Clinical audit can be a powerful way of measuring and improving service performance by reflecting on a particular aspect of the service. Clinical audit provides a means to identify and promote good practice, try out service developments and systematically measure the results. It also offers opportunities for the training and development of staff, and for joint working between staff and service users across different agencies. Critically, audit is part of a cycle of quality improvement and must lead to change: data collection is only part of the process.

Figure 3.2: The audit cycle (right)



References

26 MS patients have different levels of need. Some patients will need more than an annual review. For people with very stable MS, an annual review is offered but an appointment not made.

During our research, we found that many MS nurse teams were undertaking clinical audit, although ‘closing the loop’ was missing in some cases. MS nurses may need additional skills in this area to get the most out of audit.

Example – auditing telephone advice

Telephone consultations for people with MS have become a core element of the MS nurse service. Telephone work is often a ‘hidden’ activity which absorbs a significant proportion of nurse time but is rarely charged for and can therefore be under-valued. A challenge for MS nurses is to capture the quantity and quality of telephone work. This means auditing the time they spend on the phone, the number of patients they talk to, and the value of the advice that is provided. We have already suggested that telephone based activity should be logged, along with other activity, on an ongoing basis. The value of telephone support can also be measured by means of a simple audit, undertaken over a sample period (say 6 weeks). This could consist of:

- A log book used to record the reason for all incoming calls from patients, incorporating at the end of each call a simple question about what the patient would have done if the telephone service had not been available
- A postal questionnaire sent to patients using the service asking about their experience of it, including the quality of the advice provided and the timeliness with which their call was answered (this could be incorporated within a regular patient experience questionnaire about the MS nurse service, described in the section above)
- A calculation of the cost of the telephone service, including staff costs and call costs (for outgoing calls)

The RCN has published a good practice guide[27] on setting up and managing telephone advice lines. This includes assessment of the costs and cost-savings involved.

The MS nurses in Lambeth, Southwark and Lewisham conducted an audit[28] of their telephone clinical work in order to evaluate how effective this service is in responding to the needs of service users. The audit had three aims:

- to establish the nature of the queries that prompted patients to contact the service,
- to measure how well the MS nurses responded to these queries, and
- to establish where these queries would have been directed if telephone consultations had not been available.

The audit was based on a postal survey of service users. Patients who had contacted the service were send a questionnaire approximately two weeks after their call. The survey asked about the nature of problems/queries that prompted the call, patient satisfaction with the advice given, and what they would have done if the service had not been available.

The nurses were able to show that that their telephone service was highly regarded by service users. They also demonstrated clinical and financial benefits. The service reduced demand for alternative services, such as GPs and consultants. 64% of service users said they would have contacted their GP if they had not been able to speak to the MS nurse.

References

27 RCN (2006). Telephone advice lines for people with long term conditions. Guidance for nursing practitioners.

28 Clinical Governance Resource Group. Lambeth, Southwark & Lewisham PCTs (2007). Multiple Sclerosis Specialist Nurses. Audit of Telephone Support

3.4 Measuring patient experience of the nursing service

Measuring the experience of patients using the MS nursing service is essential, both to gather evidence on the value of the service, but also to identify areas where improvements can be made. There are many ways of measuring the patient experience, including postal or online questionnaires, telephone surveys, suggestion boxes, comment boards, discussion groups, recording individual patient stories and analysis of complaints and compliments. A combination of approaches is ideal, but a simple postal and/or online questionnaire for patients is likely to be the most practical way of gathering regular feedback. The UKMSSNA has produced a patient questionnaire, CRIMSON, which is used by many nurses. Others have developed their own tools.

The best patient experience questionnaires conform to a number of best practice guidelines, shown in Appendix F. It may be that a new patient experience survey is needed to ensure that these are met.

3.5 Making the case to local commissioners

The commissioning landscape is changing; if the Health and Social Care bill is passed, soon a different group of stakeholders will commission local neurology services, including MS nurse services. It cannot be assumed that the new commissioners will have the same goals and objectives for neurology commissioning as their predecessors. Our interviews suggested that GPs are likely to want to see nurse specialist services continue but that there are bound to be local discussions about the level of service provided and about making specialist nurse services more community-based.

> **“Generally there is an acceptance that specialist nursing roles are very valuable and no one wants to see them go – you just have to make it ‘easy’ for people to say yes to employing them, based on real data.”**
> **Commissioner**

Our judgment is that the first priority for MS nurses must be to ensure that their services are visible to GPs and their patients, and that these services are valued. It is unlikely that GPs will commission services that are unknown and/or not well regarded. There are many simple things that MS nurses can do to raise the profile of their services, such as sending out a leaflet to all GPs and GP practice managers or running lunchtime education sessions on MS for GPs and practice nurses. Many MS nurses do this already but if, however, contacts with GPs have not been made for some time, now is the right time to be renewing them. MS nurses should not take their relationship with GPs for granted. One GP we interviewed stated that his patients were badly served by existing MS services with little access to information, psychological support and follow up. This was said in spite of the fact that his practice is located in an area with a large and well-established team of MS nurses.

> **“My MS patients live in a no man’s land. They are neglected by the system. We need more community-based nurses. But I am not sure we will have the funding.”**
> **GP from Pathfinder CCG**

We also recommend that MS nurses seek early discussions with clinical commissioning groups about future commissioning arrangements. Clearly it would be impractical and unwise for MS nurses to do this alone. They should team up with other neurology health professionals, including consultant neurologists and other neurology specialist nurses. The first step should be to identify the pathfinder consortia in a given area and map these and the populations they cover against existing geographical boundaries. Commissioners should be asked about their plans and the likely timescale for the development of a neurology commissioning strategy. Timetables will be determined locally and will vary from area to area according to different factors, including the stage of development of the consortium and its overall strategic plan.

MS nurses are employed for a specific clinical role – the care of patients with MS. Not all nurses feel confident that they have the skills and knowledge to take on a broader more business-type role in which they are required to "sell" their services and engage in strategic discussions. We found some MS nurses who had well-researched business cases and service specifications to support the development of their services. Many more could not provide this sort of information and were clearly more reticent about playing this role. MS nurses would benefit from professional development geared towards improving their evaluation and influencing skills.

In the box below, we outline practical steps MS nurse specialists can take to prepare for clinical commissioning.

MS Nurses: How can you prepare for Clinical Commissioning locally?

1. Identify the clinical commissioning groups being established in your area. Go to your PCT website or the Department of Health website where there is an interactive map of pathfinder GPs **http://www.dh.gov.uk/pathfinderlearningnetwork**
2. Map the clinical commissioning groups and the populations they cover against the geographical area that you and your team currently serve.
3. Team up with other neurology health professionals, including consultants and other neurology specialist nurses. Discuss how you will approach the consortia and what your aims will be. As a team, approach the consortia in your area to find out their plans and the likely timescale for the development of a neurology commissioning strategy. Ask your PCT for help in identifying which GPs to talk to. There may be a lead GP for neurology that you can approach.
4. Make sure that the commissioning groups are well informed about the services you provide and understand their value. Write to all GPs and GP practice managers enclosing leaflets and posters which outline the services you offer. Offer to hold lunch-time education sessions for clinical staff. GPs are unlikely to commission services they know little about and do not value.
5. Begin to collect information that will convince clinical commissioners to commission MS specialist nurses and will make it easy for them to do so at the appropriate time. The sort of information that will help includes activity logs, service specifications, evidence of cost-savings and reductions in GP workloads.
6. With your team, identify gaps in existing services, for example neuro-rehab and psychological therapies. Consider what commissioners need to do to fill these gaps, and start building a case.

4 Conclusions: the way forward

MS nurses have transformed the care of thousands of people with MS. But the NHS is on the brink of a transformation, against the background of economic constraint. The move to clinical commissioning is both a threat and an opportunity for MS nurse specialists. Commissioning groups, and the GPs at the centre of them, may not be familiar with the services MS nurses provide. In the context of the challenges they have to tackle, it may be difficult to bring the topic of MS nursing to their attention. On the other hand, commissioning groups will be considering neurological commissioning with fresh eyes. There may be opportunities to commission new posts to fill gaps in coverage, and to modify existing services to respond more closely to the needs of people living with MS. Both scenarios are entirely feasible. Either way, the next two years will be challenging for MS nurses.

From our research, we have concluded that MS nurses, supported by the rest of the MS community, need to raise their profile. The case for their services is strong, but hard evidence to support it is often lacking. MS nurses must develop the skills and confidence to record, analyse and demonstrate their impact, and use this information to develop material to influence commissioners, both locally and nationally. Immediate challenges are:

- To describe clearly the different service models currently operating amongst different MS nurses and how these fit with the long term conditions agenda, as well as the wider picture of neurological services.
- To define clearly what is meant by ‘caseload’, make explicit the assumptions underpinning the idea of an acceptable caseload, and define what this is, according to service model.
- To share good practice across the MS nursing community in terms of efficient and effective working practices.
- To develop a set of ‘SMART’, evidence-based quality standards for MS nursing services, against which performance can be measured, together with an effective tool for measuring patients’ experiences.
- To create better awareness amongst MS nurses of how their services are commissioned locally, and how their role fits into the wider picture of MS services more generally, along with other neurology services and other community services; and to tailor the case to local commissioners accordingly.
- To up skill MS nurses in evaluating their services through data collection, clinical audit and measuring the patient experience.
- To bring together data on the value of MS specialist nurses to make a robust case to the commissioners of the future.

The MS community should continue to marshal the evidence on the impact of MS nurses and current gaps in services, and to campaign for the retention of existing services and the development of new ones. Only when every person with MS in the country has easy access to a high quality, specialist nursing service, will this job be done.

Appendix A: About the authors

The research for this project was undertaken by Mynors Suppiah, a consultancy working in the health sector on a range of projects aimed at evaluating and transforming health services, with a particular focus on the experience of patients and service users. The researchers were Geraldine Mynors and Sarah Perman. Additional analysis was undertaken by Martin Morse.

- **Geraldine Mynors, Director, Mynors Suppiah**.
  Geraldine has experience spanning NHS general management, consulting with McKinsey and Company, project leadership at the Department of Health Medicines Partnership Programme and information design with Consumation Ltd. She was also a Director of the Patient Information Forum (PiF) from 2010-11. Geraldine has a long track record of working in MS, having project managed the development and subsequent upgrading of the MS Decisions website. She has particular experience in patient and public involvement in healthcare and qualitative and quantitative research to measure and improve the patient experience.

- **Sarah Perman, Researcher, Mynors Suppiah**.
  Sarah was for several years a consultant working in public health and health policy with a background in project management and organisational change in the voluntary and public sectors in the UK and overseas. She has worked for NHS Westminster, the Health Protection Agency, the World Health Organization, and UNAIDS among others. Before working in health, Sarah was Director of the TUC's Partnership Institute for industrial relations and organisational change, and Senior Policy Adviser on education and training. Sarah has recently taken up a new position as Clinical Governance Manager at the Health Protection Agency.

- **Martin Morse, Morse Analytics**.
  Before founding Morse Analytics, Martin was Director of Professional Services for marketRx, a leading provider of analytics and related software services to global pharmaceutical, biotechnology and medical device companies. He developed the company's European capabilities in sales force effectiveness, marketing effectiveness and market research. He has also worked for the UK consultancy WestawayGillis as Director of Analytical Services, developing cost-effectiveness models, patient audits and bespoke software solutions for the pharmaceutical industry and NHS. He holds an MA in Mathematics and Management Studies from The University of Cambridge

Appendix B: Methodology

In the light of the rapidly changing environment in which MS nurses are operating, we adopted a pragmatic methodology designed to deliver practical recommendations within a short time frame. This consisted of desk-based research, in-depth interviews (telephone and face-to-face), and case study visits:

4.1.1 Desk-based research

We conducted a review of existing evidence and data on MS nurses. We searched the literature to identify research into the roles and impact of MS clinical nurse specialists. We used the following healthcare databases for our search – MEDLINE, PsychInfo, CINAHL and HMIC, accessed via NHS Athens. We reviewed individual articles and two literature reviews:

- Corry M., McKenna M. & Duggan M. (2011). The role of the clinical nurse specialist in MS: a literature review. The review aimed to identify research evaluating the impact of MS nurse specialists. British Journal of Nursing 20(2), 86-93.
- Forbes A., While A., Dyson L., Grocott T. & Griffiths P. (2003). Impact of clinical nurse specialists in multiple sclerosis – synthesis of the evidence. J Adv Nurs 42(5), 442-62.

We drew on documents produced by the MS Trust, MS Society and the UKMSSNA. We examined relevant documents from the Department of Health and national organisations such as the Royal College of Nursing (RCN). We reviewed the evidence from health charities which have analysed the impact of clinical nurse specialists working in other specialities. We collected business cases, telephone logs and audits from the MS nurses whom we interviewed. We also collected similar information from MS nurses through a mailing of the membership of the UKMSSNA.

4.1.2 In-depth interviews

We conducted interviews with opinion leaders and stakeholders. Interviews were conducted on the telephone or face-to-face and lasted between 45 and 60 minutes. The write-ups were analysed by looking for emerging themes.

A full list of those interviewed can be found in Appendix C. To summarise, we interviewed 33 people, of whom 17 were face-to-face, including 11 which took place during the case study visits. The breakdown of interviews is as follows:

- 12 MS nurses
- 6 consultant neurologists
- 4 commissioners
- 2 GPs
- 1 clinical services manager
- 2 patients (one a patron of the MS Trust)
- 6 representatives of national organisations and health charities

We made several approaches to GPs, particularly in the pathfinder GP consortia. Only two GPs were willing to be interviewed, others citing time pressure, reflecting perhaps the relatively low priority of this topic given the scale of the challenge they are currently facing.
We used the interviews to explore:

- the development of the MS specialist nurse role, including history, barriers and incentives;
- models of employment;
- relationships with other health professionals working in MS,
- decision-making processes around the employment of specialist nurses;
- what factors influence the decision, and how these are weighted.
- evidence of effectiveness and/or cost-savings;
- real example of business cases which have been used to make the case for employing specialist nurses;
- future commissioning arrangements.

4.1.3 Case study visits

We visited two locations in order to investigate in detail the roles and responsibilities of MS nurses in different settings. We visited Kent and Canterbury Hospital (East Kent Hospitals University NHS Foundation Trust) and the Greater Manchester Neurosciences Centre based at Salford Royal NHS Foundation Trust. The two locations were selected because they presented different models for the MS nurse service. During our visits we interviewed consultant neurologists – both generalists and MS specialists, MS nurse specialists, clinical services managers, and commissioners.

4.1.4 RCN stakeholder event

We attended and drew on information presented at an RCN roundtable on “The Future of Specialist Nursing, focusing on Multiple Sclerosis”, sponsored by Novartis, and held on 31 January 2011.

4.1.5 Project steering group

The project was overseen by a steering group which met three times – once to agree terms of reference for the project, once mid-way to review the project’s progress, and once at the end to review the findings. The steering group members were representatives of the MS Trust; Dr Peter Brex, Consultant Neurologist, King’s College Hospital; Pauline Shaw, MS Specialist Nurse, Southwark PCT; and Jane Johnson, Researcher.

Appendix C: Interviewees

With grateful thanks to all those listed below who gave up valuable time to contribute to the research.

Dr Kate Adams	Shoreditch Park Surgery, Hackney
Dr Adem Akyol	Newington Road Surgery, Ramsgate
Juliette Beaumont	MS Specialist Nurse, East Kent Hospitals University Trust
Sally Bonynge	Executive Lead for Long Term Care, Central Surrey Health
Megan Burgess	Nurse Development Advisor, Novartis and former Nurse Consultant, Salford Royal Hospital
Alison Bradford	MS Specialist Nurse, Salford Royal Hospital
Dr Peter Brex	Consultant Neurologist, King’s College Hospital
Lynne Brown	UK Programme Lead for Nursing, MS Society
Maggie Campbell	Long Term Neurological Conditions Strategy Manager, NHS Sheffield
Lesley Carter	Head of Influence and Service Development, Parkinson’s UK
Amanda Cheesley	Long Term Conditions Advisor, Royal College of Nursing
Verity Dods	MS Specialist Nurse, Surrey Community Health
Dr Martin Duddy	Consultant Neurologist, Newcastle-upon-Tyne Hospitals NHS Trust
Dr David Gosal	Consultant Neurologist, Salford Royal Hospital
Juliet Greenwood	MS Specialist Nurse, North Cumbria University Hospitals
Huseyin Huseyin	MS Advanced Nurse Practitioner, Luton & Dunstable Hospital/Chair, Multiple Sclerosis Specialist Nurse Association
Susan Holmes	MS Specialist Nurse, East Kent Hospitals University Trust
Fran Jackson	MS Specialist Nurse, Salford Royal Hospital
Sarah Joiner	Patron, MS Trust
Tim Jones	Independent Commissioning Consultant
Alison Leary	Macmillan Lead Cancer Nurse, Royal Brompton and Harefield Hospital
Louise Maile	Joint Commissioner for Physical Disabilities and Sensory Needs, NHS Westminster
Susan Oliver	Independent Nurse Consultant Rheumatology
Faye Penston	Clinical Services Manager, East Kent Hospitals University Trust
Wendy Power	MS Specialist Nurse, Salford Royal Hospital
Debbie Quinn	MS Specialist Nurse, Northamptonshire Healthcare NHS Trust
Dr Ian Redmond	Consultant Neurologist, East Kent Hospitals University Trust
Julie Rigby	Greater Manchester Neurosciences Network Director, NHS Salford
Dr David Rog	Consultant Neurologist, Salford Royal Hospital
Pauline Shaw	MS Specialist Nurse, Southwark PCT
Maureen Speed	MS Specialist Nurse, East Kent Hospitals University Trust
Dr Paul Talbot	Consultant Neurologist, Salford Royal Hospital Trust
Delyth Thomas	MS Specialist Nurse, Herefordshire PCT
Liz Wilkinson	MS Specialist Nurse, Central Surrey Health
David Yeandle	MS patient, Hampshire

Appendix D:

Primary Care Organisations (PCOs) by Quintile in terms of nurse coverage per 1000 population[29]

Quintile 1 (most MS nurse coverage)	Quintile 2	Quintile 3	Quintile 4	Quintile 5 (least MS nurse coverage)
Abertawe Bro Morgannwg	Barnet	Barking and Dagenham	Ashton, Leigh and Wigan	Betsi Cadwaladr University
Aneurin Bevan	Bath and North East Somerset	Barnsley	Bedfordshire	Birmingham East and North
Ayrshire & Arran	Belfast HSCT	Bassetlaw	Bolton	Blackburn with Darwen
Borders	Bexley	Berkshire East	Brighton and Hove City	Blackpool
Brent	Bournemouth and Poole	Berkshire West	Bromley	Bury
Cambridgeshire	Bristol	Bradford and Airedale	County Durham	Calderdale
Camden	Buckinghamshire	Central and Eastern Cheshire	Darlington	Central Lancashire
Cardiff and Vale University	City and Hackney	Coventry	Derbyshire County	Croydon
Cwm Taf	Cornwall and Isles of Scilly	Devon	Doncaster	Derby City
Dumfries and Galloway	Cumbria	Ealing	Dudley	East Lancashire
East Sussex Downs and Weald	Dorset	Fife	East Riding of Yorkshire	Greater Glasgow & Clyde
Forth Valley	Eastern and Coastal Kent	Gloucestershire	Gateshead	Halton and St Helens
Great Yarmouth and Waveney	Enfield	Grampian	Harrow	Hastings and Rother
Hammersmith and Fulham	Greenwich	Havering	Hartlepool	Heywood, Middleton and Rochdale
Highland	Hampshire	Heart of Birmingham	Hull	Hillingdon
Hywel Dda	Haringey	Hertfordshire	Leeds	Knowsley
Isle of WightIslington	Herefordshire	Kingston	Luton	Lanarkshire
Kensington and Chelsea	Hounslow	Mid Essex	Manchester	Leicester City
Medway	Kirklees	Newcastle	Middlesbrough	Leicestershire County and Rutland
Milton Keynes	Lambeth	North East Essex	North East Lincolnshire	Lincolnshire
Norfolk	Lewisham	North Staffordshire	North Lincolnshire	Liverpool
Northumberland	Newham	North Tyneside	Oldham	Lothian
Orkney	North Somerset	Northamptonshire	Peterborough	North Lancashire
Oxfordshire	North Yorkshire and York	Redbridge	Redcar and Cleveland	Plymouth
Portsmouth City	Northern HSCT	Rotherham	Salford	Sefton
Richmond and Twickenham	Nottingham City	Sandwell	Somerset	Solihull
Shetland	Nottinghamshire County	Shropshire County	Southampton City	South Birmingham
South East Essex	Powys	South Tyneside	Stockport	Sunderland
South Eastern HSCT	Sheffield	Stoke on Trent	Stockton-on-Tees	Swindon
South Staffordshire	South Gloucestershire	Surrey	Suffolk	Torbay
South West Essex	Southwark	Telford and Wrekin	Sutton and Merton	Wandsworth
Southern HSCT	Tower Hamlets	Wakefield District	Tameside and Glossop	Warrington
Tayside	West Essex	Walsall	Trafford	Western Cheshire
West Kent	West Sussex	Warwickshire	Waltham Forest	Western Isles
Western HSCT	Wolverhampton City	Westminster	Wiltshire	Wirral
		Worcestershire		

References

[29] Note: Based on MS Trust survey of MS nurses, September 2011. PCOs within each of the quintiles are arranged alphabetically, not ordered by nurse availability. It should be noted that this picture is changing constantly. Because the number of MS nurse posts is low (on average less than one per PCO), reducing or expanding by a single post can move a PCO from the top to the bottom quintile. In addition, the configuration of PCOs is changing rapidly, with PCT clusters being formed in the latter part of 2011.

Appendix E: MS cost calculation tools

The MS Society cost calculator is an excel spreadsheet which can be used to calculate the actual cost of employing a specialist nurse against the cost savings from avoided admissions and other attendances, based on the national tariff. Evidence for avoided admissions is recorded on a UKMSSNA pro forma.

The MSS cost calculator has been around for several years and is now in its fifth revision. MS nurses can obtain the cost calculator from the MS Society's Service Development Officers.

The MSS cost calculator was used to estimate the savings made in mid-Surrey, and in our model shown in Figure 2.2. However, it is what it says: a calculator. It does not generate the assumptions about how many admissions or attendances have been avoided.

Neuronavigator (**www.neuronavigator.org.uk**) is an on-line tool developed by Neurological Commissioning Support with financial support from Bupa. Neurological Commissioning Support is a joint initiative of the MND Association, MS Society and Parkinson's UK. It exists to provide PCTs and local authorities with practical support in commissioning services for people with long term neurological conditions.

Neuronavigator is directed at commissioners who are planning services for neurological conditions in their area. It is not designed to record cost savings so it is less useful for MS nurses than the MS Society Cost Calculator. However, there is useful information within the tool on national costs. Neuronavigator allows you to use pre-entered information on activity levels and cost or to enter your own information based on local data. Once the population size is entered, the tool will calculate prevalence for a particular condition – or you can enter your own information on prevalence in your area. It then automatically calculates the costs associated with each condition, broken down into services, equipment, medication and other costs. Cost are based on national tariff data. Assumptions about local costs are justified in information provided on the website.

Appendix F: Best practices in measuring patient experiences

In our experience, the best patient experience surveys conform to the following guidelines:

Approach a representative sample of patients	Make sure you talk to all the different groups of patients you serve. If you have the time and resources to survey the entire caseload then great, but if not, choose patients randomly from the caseload. Don't leave people out because they haven't used the service in the past year (you need to find out why not), or because they are seen in a particular clinic or area.
Make the survey anonymous	Don't ask for identifying details such as name or exact age. Give a reassurance in the questionnaire that the results will be anonymous and confidential, and sort out a system so that the questionnaire can be sent back to someone other than the MS specialist nurse for analysis.
Ensure the survey is accessible to all	Make sure that people with more advanced disability aren't excluded from taking part. If you can, offer a telephone option (perhaps through specialist nurse in another specialty – and you can do the same for him/her) so that patients can phone in with their responses if they have trouble writing.
Use a mixture of quantitative and qualitative questions	Quantitative questions are useful for gathering hard data which can then be compared from one time period to the next. Using a Likert scale (1 = strongly disagree through to 5 = strongly agree) can be a good way to do this, and offers more choice than 'Yes/No', which is very restrictive. Including a net promoter score question (On a scale of 1-10, how likely would you be to recommend the MS nurse service to a friend with MS?) can give a very useful summary measure which can be tracked over time. Qualitative questions capture the things which respondents can't say in numbers and will give you the richer, more detailed quotes that can help make the case for your service or help you understand why people have given the quantitative responses they did.
Avoid leading questions	Tempting as it may be to ask a question like 'Tell us in 10 words why your MS nurse is fantastic', the results you get back will have less credibility, and you will frustrate respondents who want to tell you about ways to improve! Ask a balance of questions asking for positive feedback and areas where the service could be better.
Ask about all the important dimensions of patient centred care	Keep the questionnaire manageable, but make sure you ask about all the most important topics for patients. The King's Fund[30] recommends asking questions from the Institute of Medicine domains of patient-centred care, which are: • Respect for patient preferences and values, including shared decision making • Co-ordination and integration of care (which would include accessibility of services) • Information communication and education • Physical comfort (which would include the clinic setting) • Emotional support – relieving fear and anxiety • Involvement of family and friends / carers
Pilot the questionnaire before using it	Ask a few patients (3-4) to give the questionnaire a try before you send it out widely, and ask for their feedback on whether the questions were clear and comprehensive, and how easy they found it to complete.

References

[30] King's Fund: What matters to Patients? (research in progress, reporting 2012). See http://www.kingsfund.org.uk/topics/patientcentred_care/

Further reading:

- Understanding what matters: a guide to using patient feedback to inform services, Deparment of Health, 2009 (available from **www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_099779.pdf**)
- The NHS Institute Patient Experience Network webpages include how-to guides and short films – see **www.institute.nhs.uk/share_and_network/pen/how_to_measure_patient_experience.html**

Appendix G: Economic evidence from other specialties

1. Key findings of a rheumatology telephone helpline

A recent study was able to show how a telephone helpline run by specialist nurses in a district general hospital benefits rheumatology patients and the NHS. The rheumatology helpline was audited by:

- a postal questionnaire to assess patient satisfaction;
- a helpline log book used to record the nature and outcome of all calls;
- this retrospective analysis was used to calculate cost-savings achieved by the helpline.

The study found that 60% of patients would have made an appointment with their GP if they had not been able to speak to a specialist nurse. Of those returning questionnaires, 95% were satisfied with the help they received.[31]

2. Frontier Economics research on cancer nursing

The Government recently commissioned a report on the costs and benefits of employing "one to one support workers" for cancer patients in England. This term included clinical nurse specialists, nurses at lower grades and care coordinators.

The study modeled costs and benefits for different mixes of grades of staff. Benefits arose from reductions in emergency bed days, and reductions in appointments with consultants and GPs.

The report estimated that a net saving of £19m could be achieved across England for several adult cancers and all children and young people's cancers.[32]

3. Pandora research on rheumatology nursing

Rheumatology nurses have been able to demonstrate their value through a recent RCN project. The RCN used an electronic workload modeling tool called Pandora to record the activities of nurse specialists. The log of nursing activity showed that the majority of interventions were clinical. Pandora also recorded patient outcomes from a developed consensus list.

A financial value was attached to the nurses' activity. This led to the conclusion that the outpatient work done by rheumatology nurses is worth £72,128 per nurse (WTE) per annum and saves £175,168 per nurse per annum by freeing up consultant appointments. Telephone advice was also found to reduce the number of GP appointments thereby saving £72,588 per annum.[33]

References

31 Hughes R., Carr M., Huggett A. &Thwaites C. (2002). Review of the function of a telephone helpline in the treatment of outpatients with rheumatoid arthritis. Ann Rheum Dis, 61, 341-345.

32 Frontier Economics Ltd (2010). One to one support for cancer patients.

33 RCN (2010). Clinical nurse specialists: adding value to care – an executive summary.

4. Key findings from Parkinson’s UK

Parkinson’s UK has found that an estimated £56 million could be saved through the development of community-based services for people with Parkinson’s. They have also found that a Parkinson’s nurse can reduce hospital admissions by 50%. In Harlow, data on admissions before and after the appointment of a Parkinson’s nurse was analysed. It showed that the Parkinson’s nurse, working as part of a multi-disciplinary team, was able to save the trust £80,000 through a reduction in hospital admissions and earlier hospital discharge.[34]

5. Key findings from the British Heart Foundation

The British Heart Foundation has been running a programme to fund and support cardiac nurses for more than fifteen years. There are now 426 cardiac nurses across the UK. A recent evaluation by the University of York found the nurses achieved:

- a reduction in all cause admissions by an average of 35%
- a net saving of approximately £1,826 per patient after the cost of the nurse’s salary had been deducted
- collectively, total savings to the NHS of more than £8 million in a single year.[35]

References

[34] Parkinson’s Disease Society (2006). Commissioning Parkinson’s services. The clinical and financial value of Parkinson’s disease nurse specialists.

[35] Pattenden J. et al (2008). The development and impact of the British Heart Foundation and Big Lottery Fund Heart Failure Specialist Nurse Services in England: Final Report.

Appendix H:
Key policy and research papers on MS nurses, and selected papers on specialist nursing more generally

Adelphi International Research (2010). European Multiple Sclerosis (MS) nurse survey – Key UK findings. This survey finds that the MS nursing role in the UK is probably the most advanced in Europe, with nurses playing a greater clinical role than their European counterparts.

British Heart Foundation (2010). BHF Specialist nurses – changing the face of cardiac care. Review of the achievements of BHF-funded nurses, including home based patient care and cost savings for the NHS.

Corry M., McKenna M. & Duggan M. (2011). The role of the clinical nurse specialist in MS: a literature review. British Journal of Nursing 20(2), 86-93. This review aims to identify research evaluating the impact of MS nurse specialists.

Department of Health (2005). National Service Framework for Long Term Neurological Conditions. This sets out 11 quality requirements for management of people with long term neurological conditions, and models for commissioning and service delivery.

Department of Health (2010). National cancer patient experience survey programme – 2010: national survey report. The survey examines the experiences of cancer patients across England in the first three months of 2010. The report shows a strong association between support from a clinical nurse specialist and improved patient experience.

Department of Health (2010). NHS Outcomes Framework 2011/12. This sets out the national outcomes and corresponding indicators that will be used to hold the new NHS Commissioning Board to account.

Forbes A., While A., Dyson L., Grocott T. & Griffiths P. (2003). Impact of clinical nurse specialists in Multiple Sclerosis – synthesis of the evidence. J Adv Nurs 42(5), 442-62. Systematic review examining the role of the MS nurse.

Frontier Economics Ltd (2010). One to one support for cancer patients. Modeling for the Department of Health of the cost effectiveness of one to one support roles, provided by clinical nurse specialists, care coordinators, and staff at lower grades.

Hill J. (2007). Editorial. Rheumatology nurse specialists – do we need them? Rheumatology 46, 379–381. Review of the role and impact of rheumatology nurse specialists.

Hughes R., Carr M., Huggett A. & Thwaites C. (2002). Review of the function of a telephone helpline in the treatment of outpatients with rheumatoid arthritis. Ann Rheum Dis 61, 341-345.

Johnson J., Smith P. & Goldstone L. MS Research Trust and Southbank University (2001). Evaluation of MS specialist nurses. A review and development of the role. This research uses a range of methods to explore the development of the specialist nurse role. It found evidence of valuable support for patients and their families, and cost savings for the NHS.

Macmillan (2010). Allied Health Professionals in cancer care: an evidence review. Review of the work of Macmillan funded posts and the impact on cancer patients.

MS Society. Heinonen R. & Dorning H. (2011). Experiences of people using MS specialist nurse services. Survey of people with MS who have used the services of a MS specialist nurse.

MS Trust (2011). Survey of MS nurses. Reviews the needs, aspirations and background of MS specialist nurses.

NHS National Cancer Action Team & Macmillan (2010). Quality in nursing. Excellence in cancer care: The contribution of the clinical nurse specialist. Guide for commissioners and managers on the contribution of clinical nurse specialists to cancer care.

NICE (2004). Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care. NICE clinical guideline for diagnosis and treatment of people with MS.

Oliver S. & Leary A (2010). The value of the nurse specialists' role: Pandora initial findings. Journal of Musculoskeletal Care 8, 175-177. Analysis of an RCN research project, showing cost-savings of £225,000 per annum per WTE nurse.

Parkinson's Disease Society (2006). Commissioning Parkinson's services. The clinical and financial value of Parkinson's disease nurse specialists. Summary of the role and cost benefits of nurse specialists working in the field of Parkinson's.

RCN (2006). Telephone advice lines for people with long term conditions. Guidance for nursing practitioners. The document outlines steps in developing cost-effective, high quality telephone helplines.

RCN (2009). Rheumatology nursing. Results of a survey exploring the performance and activity of rheumatology nurses. The survey highlights the qualifications, training needs and work productivity of rheumatology nurses.

RCN (2010). Clinical nurse specialists: adding value to care – an executive summary. Report of an RCN research project to examine the roles of clinical nurse specialists working in the field of rheumatology.

RCN (2010). Guidance on safe nurse staffing levels in the UK. Report outlining the principles for safe nursing levels, and reviewing the range of methods for workforce planning.

RCN (2010). RCN Policy Position. Evidence-based nurse staffing levels. Position paper to inform analysis of safe staffing levels.

RCN (2010). Specialist nurses. Changing lives, saving money. Case studies of specialist nurses working in different fields - the document makes the case for protecting posts at risk.

RCN, Parkinson's Disease Society & Multiple Sclerosis Society (2006). Report from a symposium examining the interface between community matrons and specialist nurses for Parkinson's disease and Multiple Sclerosis. This report outlines the separate and complementary roles of community matrons and specialist nurses in managing patients with long term neurological conditions.

Skills for Health – Workforce Projects Team (2009). Long term neurological conditions. A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse. Advice for commissioners and service providers on service redesign, clarifying the contribution of specialist nurses and the value of multidisciplinary teams.

Thwaites C., Ryan S. & Hassell A. (2008). A survey of rheumatology nurse specialists providing telephone helpline advice within England and Wales. Rheumatology 47, 522–525. A review of telephone helpline services and associated protocols and training.

UKMSSNA (2007). Multiple Sclerosis Specialist Nurses. The document demonstrates how MS nurses are contributing towards the DH Standards for Better Health (2006).

UKMSSNA, MS Trust & RCN (2001). Specialist nursing in MS. The way forward. Guidance for commissioners and NHS managers on employment of specialist MS nurses, including job roles, job descriptions, clinical supervision, standard setting, and audit.

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