



MS specialist nursing in the UK - 2014

This report presents the findings of a national survey of UK multiple sclerosis specialist nurses conducted by the MS Trust

Objectives

In March 2014, the MS Trust conducted a national survey of MS specialist nurses (MSSNs) in order to:

- confirm the number of MSSNs in the UK
- clarify any difference between number of posts (headcount) and whole time equivalent (WTE) workforce
- indicate whether there is a shortfall in MSSN posts
- describe the balance of funding for MSSNs between the NHS and other sources
- identify the current challenges facing UK MS specialist nursing
- identify regional variation in the provision of MS specialist nursing across the UK.

This preliminary analysis of the survey responses addresses the first four of these objectives. Further work on the challenges facing UK MS specialist nurses and a more detailed regional analysis will follow later in 2014.

Key Findings

- There are 245 MS specialist nurses (100% MS caseload) in the UK, whose whole time equivalent hours equate to a workforce of 216.
- There is variation in availability of MS specialist nurses between the UK countries. The MS Trust will be undertaking further work on the regional distribution of MS nurses and their accessibility for people with MS.
- There is a clear shortfall of MS specialist nurses of between 126 and 214 whole time equivalent posts across the UK. Further work is required on optimal caseloads for different types of services and to map areas of under-provision within each country to support targeted recruitment.
- Nearly 90% of MS specialist nurses are wholly funded by the NHS. Only 18 nurses (16 of them in England) reported being wholly or partly funded by a pharmaceutical company.
- More than 40% of MS specialist nurses based in England cover three or more Clinical Commissioning Groups (CCGs). By contrast, the situation in Scotland is more stable with MSSNs generally relating to only one Health Board.



Methodology

A self-report survey was undertaken of all specialist nurses working in MS on the MS Trust database. These were nurses categorised as MS specialist nurses (MSSN) (with a 100% MS caseload) or neurology specialist nurses (NSN) (with a caseload that includes MS). A small number of additional MS nursing roles were also included, including MS support or MS liaison nurses.

The survey was conducted between 10 March and 10 April 2014. The survey was launched at the MS Trust annual MS specialist nurses' meeting and delegates responded by hand held voting device. Following the meeting, the remainder of eligible nurses on the database were contacted by email and asked to complete the survey online. Follow-up emails and calls were made to remind people to complete the survey.

All respondents were asked to provide their name, allowing the MS Trust to map the results back to the database and to enable subsequent geographic analysis of the data. The results below, however are presented anonymously.

The survey was sent to 283 specialist nurses working in MS* taken from the MS Trust health professional database. The cohort included MSSNs and NSNs**:

	Total	Responders	Non Responders	Not contacted***	Response rate of asked	Response rate of all
MS specialist nurses	245	237	6	2	98%	97%
Neurology specialist nurses	38	35	1	2	97%	92%
ALL	283	272	7	4	97%	96%

* The survey was also sent to 41 nurses who work in MS services in other roles. This includes MS support nurses (including those employed by pharmaceutical companies), infusion nurses and other roles which don't fit the criteria of MSSN or NSN. Their responses are excluded from this analysis.

** Neurology specialist nurses (NSNs) cover a mixture of long-term neurological conditions. Their available time for MS varies and is dependent on the number and nature of other conditions on their caseload. Their contact with the MS Trust for professional development will also vary so it is likely that there are NSNs not included on the MS Trust database. Data was collected on NSNs known to the MS Trust but was excluded from this analysis.

*** 4 nurses were excluded from the survey due to personal circumstances known to the MS Trust.

2 MSSNs - due to long-term sickness absence.

2 NSNs - due to ill health in the family or maternity leave.



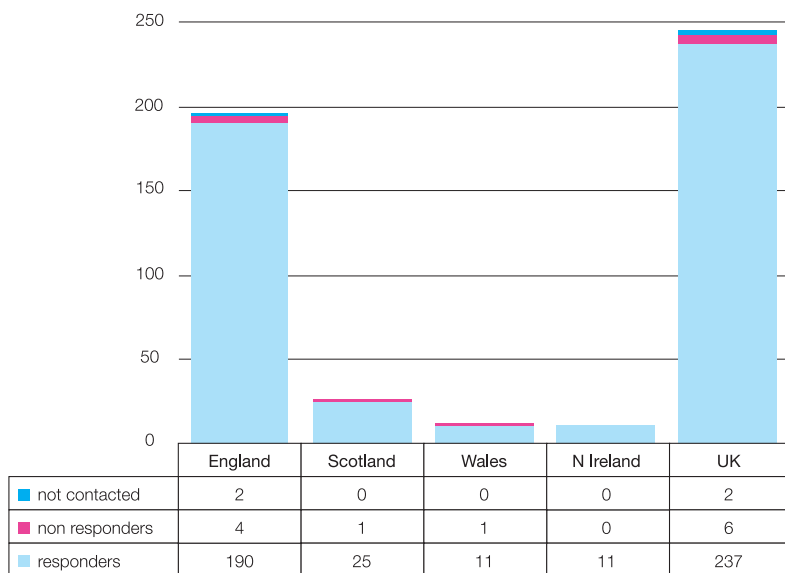
The response rate from the 245 UK MS specialist nurses was 97%.

Results

MS Specialist Nurses

The MS Trust is in contact with **245** MSSNs across the UK and is confident that this represents all of the MSSNs working in the NHS in April 2014. The overall response rate to the survey from the MSSNs was **97%**.

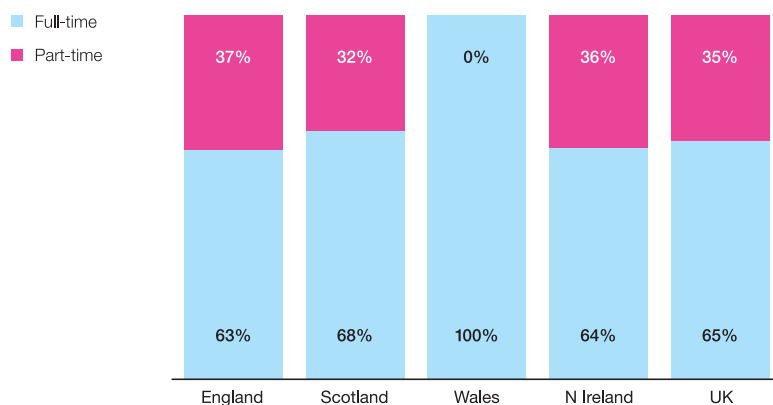
MSSN respondents



Headcount versus whole time equivalent posts

MSSNs were asked to identify themselves as full or part-time. With the exception of Wales, where all MSSNs reported that they are in full-time posts, approximately 1/3 of MSSNs are in part-time roles.

Full-time v part-time MSSNs



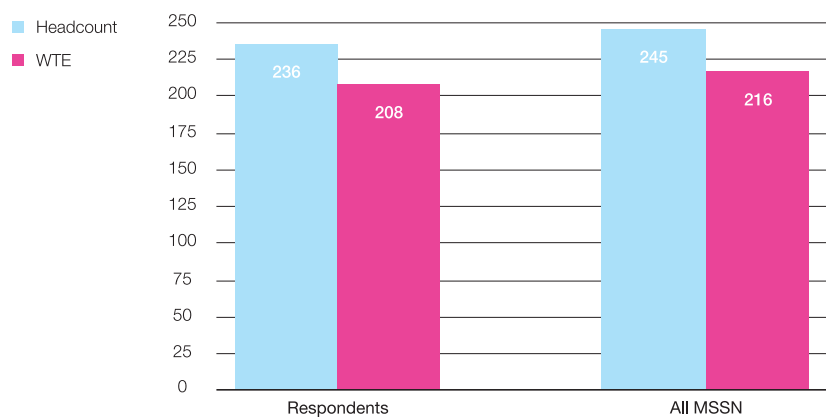


There is currently no comprehensive MS register in any UK country and no consensus about the number of people with MS in the UK.

Part-time MSSNs were asked for their whole time equivalent (WTE) hours. In some cases, respondents put their actual hours worked. These were converted to WTE figures assuming a 37.5 hour full-time working week.

This data allowed us to calculate the difference between the number of MSSNs and the WTE workforce. We found that the WTE for survey respondents was 88% of the number of nurse posts. Given the high response rate to the survey, we were able to extrapolate to the full cohort of MSSNs to calculate an overall WTE for MSSNs in the UK. In other words, in terms of available MSSN time to deliver services, there is the equivalent of 29 fewer MSSNs across the UK than the total number of posts would indicate.

MSSN posts v WTE (UK)



Availability of MS specialist nurses

The MS Trust has a comprehensive map of all MS nurses in the UK (www.mstrust.org.uk/map). The MS Trust will be undertaking further analysis of the survey data to describe regional variations in availability of MS nurses as well as challenges they face within their local health service context.

One important measure of availability of MS services is the number of people with MS per MS nurse. This calculation relies on accurate data regarding the number of people with a diagnosis of MS in the UK, nationally and regionally. There is currently no comprehensive MS register in any UK country and no clear consensus about prevalence data. The generally accepted figure for the UK has been around 100,000 people¹. A recent epidemiological study estimates the number as significantly higher at 127,000². In the absence of a single agreed figure, we have presented the availability of MS nurses as a range, using the higher and lower prevalence figures as the boundaries. This equates to around 480 people with MS per MSSN.

¹mstrust.org.uk/information/aboutms/keyfacts.jsp [accessed 1 May 2014]

²Mackenzie IS, et al. Incidence and prevalence of multiple sclerosis in the UK 1990-2010: a descriptive study in the General Practice Research Database. *J Neurol Neurosurg Psychiatry* 2014;85(1):76-84.



Across the UK, there are currently around 550 people with MS per WTE MS specialist nurse.

People with MS per MSSN (nurse headcount)
(ranges based on current range of MS prevalence data)



*Further analysis of MSSNs in Wales is required. There are some MSSNs based in England who work across the border, which will affect availability in both countries.

Applying prevalence figures to the WTE calculation for MSSNs shows a realistic picture of the number of people with MS per MSSN. Across the UK, this means that there are currently around 550 people with MS per MSSN.

People with MS per MSSN (WTE)

(ranges based on current range of MS prevalence data)



*Further analysis of MSSNs in Wales is required. There are some MSSNs based in England who work across the border which will affect availability in both countries.



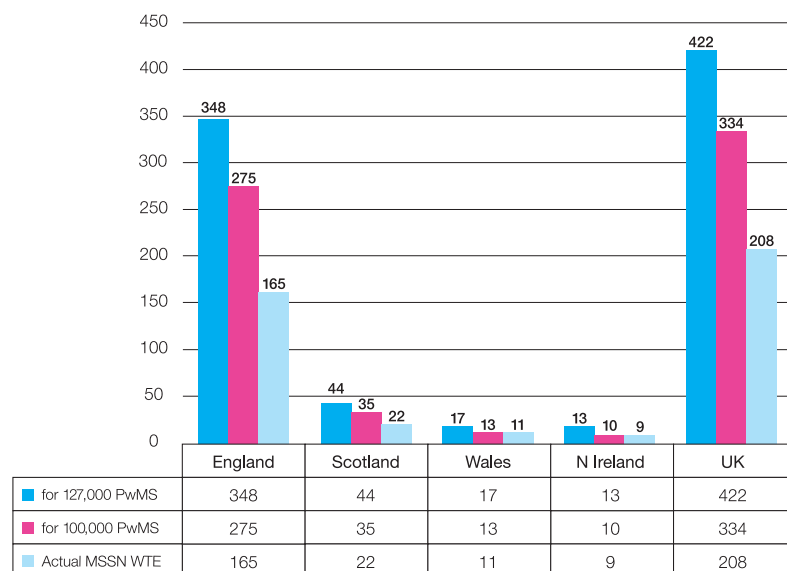
To reach the target of around 300 people with MS per WTE MS specialist nurse, between 126 and 214 more posts are needed.

Shortfall in MSSNs

In addition to agreement on prevalence, to calculate the required number of MSSNs for the UK requires some consensus on an acceptable caseload. Recent work by the MS Trust suggests, on average, an optimal caseload of around 300 patients per whole time equivalent nurse. This is not a definitive figure and there are many factors which can affect the appropriate size of caseload for different types of service. This includes service configuration and caseload characteristics, such as proportion of patients who may be on disease modifying therapy, proportion with progressive MS who may also have complex symptoms and disability, service rurality and the availability of other services such as psychology and therapies.

As part of the GEMSS programme (Generating Evidence in MS Services), the MS Trust will be modelling optimal caseloads for different types of services with different caseload characteristics. This will allow for a more detailed analysis of caseload. As an average, however, the caseload figure of 300 does allow a calculation of shortfall in MSSNs. The following chart shows the shortfall based on the higher and lower MS prevalence figures*.

Requirement for MSSN posts compared to available MSSNs
Assuming an optimal caseload of 300 people with MS (PwMS) per MSSN



To achieve an optimal caseload of 300 people with MS per MSSN, the shortfall for the UK is between 126 and 214 WTE posts. The scale of shortfall varies between countries, with England apparently having the lowest levels of availability. Further mapping work is required to identify specific areas of under-provision which could support targeted recruitment and ensure consistency in accessibility as well as availability.

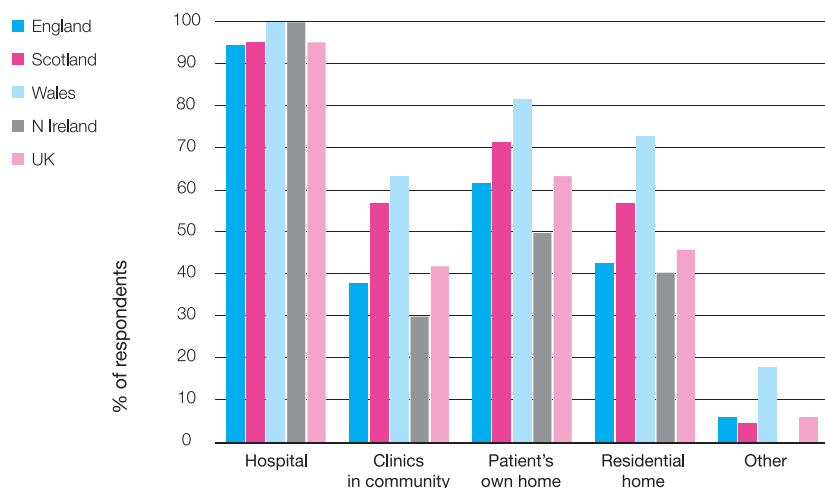
* Making judgements about caseload for MSSN services which cover the wide spectrum of MS care in different settings and at all points on the disease continuum is problematic but crucial work. It is important to treat these estimates with caution and see them within the context of the overall findings of this survey as well as the ongoing work on caseloads.



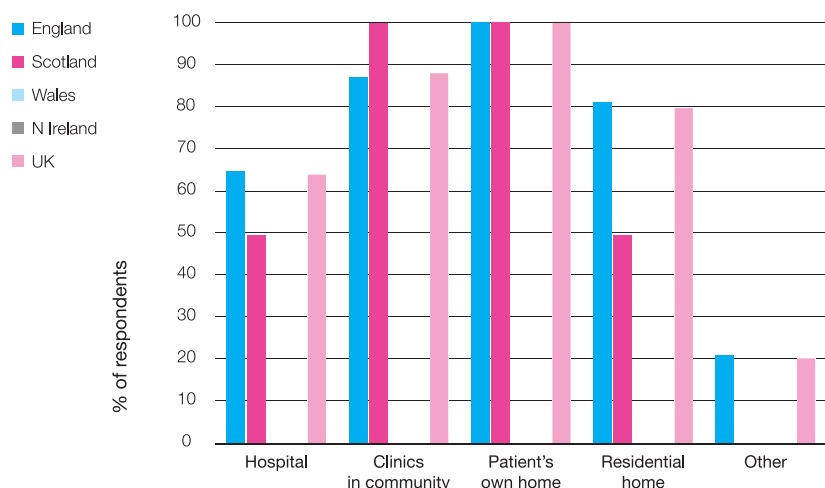
Where MSSNs see people with MS

Respondents were asked where they see people with MS. They could select as many locations as applied to their service. Regardless of whether their principal base is a hospital or the community, over 70% of MS specialist nurses reported that they see patients in more than one setting. Overall, we found that 60% of nurses employed in hospitals also see patients in their own homes and 64% of community MSSNs also see patients in hospital. However, particularly in England and Northern Ireland, less than 40% of hospital based MSSNs also provide community clinics. Further analysis is required to determine whether these areas have access to community based MSSNs, particularly for those people with complex disabilities.

Where hospital based MSSN see patients



Where community based MSSN see patients





Overall, 87% of MS specialist nurses are solely funded by the NHS.

MS specialist nurse funding

Nurses were asked about the funding for their post. Overall, 87% reported that they were solely funded by the NHS.

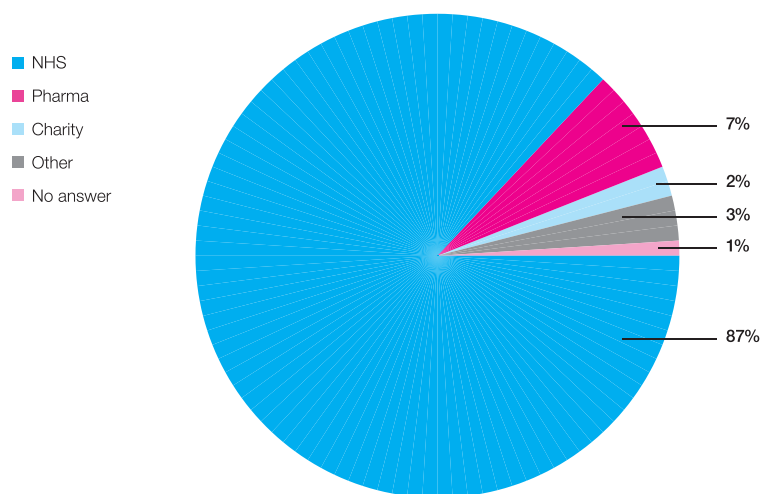
In Scotland, one MSSN reported being solely funded by a pharmaceutical company and an additional three being wholly or partly funded by a charity.

In Wales, no MSSN reported being wholly or partly funded by a pharmaceutical company or a charity.

In Northern Ireland, one MSSN reported being wholly funded by a pharmaceutical company and none reported being funded by a charity.

In England, 12 MSSNs reported being solely funded by a pharmaceutical company with an additional four reporting mixed funding from a pharmaceutical company and either the NHS or another source. Two MSSNs based in England reported being wholly or partly funded by a charity. Though funding for MSSNs in England is predominantly through the NHS, the detailed picture is complex and fluid. Depending on employer, service model and, to some extent, caseload, MSSN posts are funded either through national specialised commissioning by NHS England or through local Clinical Commissioning Groups (CCGs). There is a widespread lack of clarity about commissioning responsibilities and a well-documented need to create efficiencies across the NHS which generate real savings³. Further analysis is required to fully describe the detailed NHS funding arrangements for MSSNs and other elements of MS services.

Source of funding for MSSN
number of posts



³Bowen A, Hughes S. Getting it right for people with MS. Commissioning 2014, 1(1): 28-30.



42% of MS specialist nurses in England reported covering three or more Clinical Commissioning Groups.

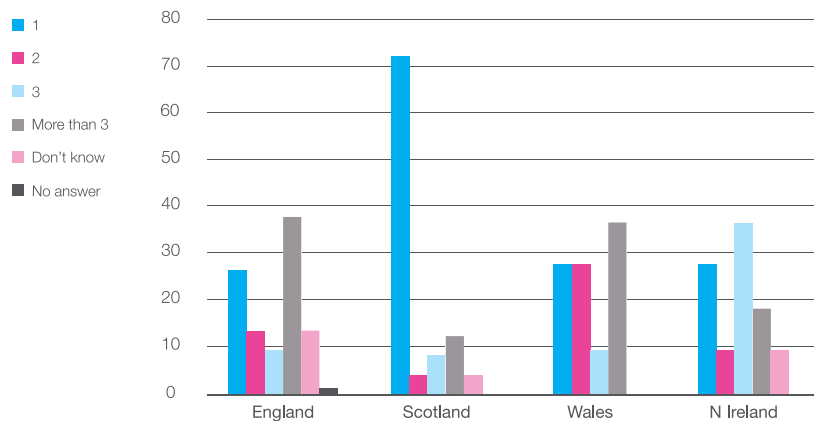
MS specialist nursing in the reformed NHS in England

The recent reforms to the NHS in England have had a significant impact on the way in which MS services are commissioned and funded. Other work undertaken by the MSTRust has highlighted the importance of MSSNs demonstrating their value and impact to managers and commissioners⁴. With the larger number of CCGs and the complexity of funding through clinical and specialised commissioning described above, this inevitably becomes a significantly more difficult task.

Nurses were asked how many CCGs or Health Boards they covered. The picture is complex, particularly in England and Wales - 42% of MSSNs reported covering three or more boards/CCGs - and also confusing - one in eight nurses didn't know how many boards/CCGs they cover. There is a clearly a need for these MSSNs to know who is commissioning and/or funding their service and to ensure they are collecting the appropriate evidence to demonstrate their value to each of these audiences. Consistency on the part of CCGs in the data they require would simplify the task of the MSSNs to meet their respective needs.

By contrast, the situation in Scotland would appear more stable with most MSSNs knowing how many Health Boards they cover and over 70% covering only one. There are also clearly identified standards relating to MS nursing.

CCGs / Health Boards covered



⁴Mynors G, et al. Defining the value of MS specialist nurses. Letchworth: MS Trust; 2012.



The MS Trust will be mapping areas of under-provision of MS specialist nurses to help ensure equitable access for everyone with MS.

Conclusion

MS specialist nursing in the UK has grown steadily over the past twenty years and is a well-established and vital element of a high quality MS service. The response rate to the survey indicates a strong level of engagement by the community of MSSNs to ensure there is accurate data about their roles, sources of funding for their posts and the challenges they face in their local context as well as from changes in the wider healthcare context.

In order to provide service managers and commissioners from both national specialised commissioning and local CCGs with relevant information, the MS Trust will be undertaking further analysis of the survey data to determine:

- ▶ Regional distribution of MSSNs
- ▶ Mapped areas of under-provision by UK country
- ▶ Models of optimal caseloads for different service types
- ▶ Analysis of current challenges for MSSNs

MS is the most common disease of the central nervous system affecting young people. MS is a lifelong condition. It is fluctuating and variable, with a wide array of symptoms and people with MS face uncertainty about how they will be affected by the condition. Everyone with a diagnosis of MS should have easy and timely access to an MS specialist nurse who can provide them with the specialist knowledge and support they require to remain active, engaged and as well as possible. This survey helps strengthen the case for continued focus on the availability of MS nurses across the NHS.

⁵NHS Quality Improvement Scotland. Neurological health services: clinical standards. Edinburgh: NHS Quality Improvement Scotland; 2009.

⁶MS explained. Letchworth: MS Trust; 2013.



For further information on this report and work by the MS Trust on MS specialist nursing and other services, please contact Amy Bowen, Director of Service Development (amy.bowen@mstrust.org.uk).

Acknowledgements

The MS Trust would like to thank all the MS specialist nurses who responded to the survey.

About the MS Trust and this survey

The MS Trust is a national charity which works to make a real difference to people with MS.

For over 10 years, the MS Trust has run a national programme of education, education bursaries, mentoring and professional development for health professionals working with people with MS. The programme focusses principally on MS specialist nurses (MSSNs) and on allied health professionals (AHPs) working in MS. The education events, bursaries and mentoring elements of the programme are funded through investment made by the MS Trust and the corporate partners in the Department of Health Risk-sharing Scheme.

The MS Trust has a close relationship with most of the MSSNs in the UK. The Trust keeps an up-to-date database and map of MSSNs, to help signpost people with MS to their nearest MSSN as well as to monitor availability of services. The MS Trust has a high degree of confidence in the comprehensiveness of the MSSN database.

Published May 2014



Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T. **01462 476700**
T. **0800 032 3839**
E. info@mstrust.org.uk
www.mstrust.org.uk

Registered charity no. 1088353

