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Measuring the burden of hospitalisation in multiple sclerosis: A cross-sectional analysis of the English Hospital Episode Statistics database 2009-2014

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Executive summary

This report has been jointly written by NHiS Commissioning Excellence and the Multiple Sclerosis Trust to highlight how better, more cost-effective services can be delivered for people with MS.

Care for people with MS, especially unplanned care, is currently a huge burden to the NHS. In 2013/14 non-elective hospital admissions for people with MS in England cost the NHS £43 million.

The most common reasons for these admissions are infections, urinary tract and respiratory, pneumonia and MS itself (including MS relapse). With more focus on anticipatory care, many of these costly admissions could be prevented and the quality of life for people with MS vastly improved. Furthermore the money saved could be invested in the provision of more proactive care.

An important factor is identifying at-risk patients and addressing the issues before the onset of a crisis. MS nurse specialists are ideally placed to identify this group of patients and provide proactive care, also involving GPs, neurologists, allied health professionals and community services.

Better data is key if commissioners are to make these much needed improvements and plan better services for people with MS. A better understanding of the prevalence of MS both nationally and locally at CCG level, as well as improving the admissions data that CCGs are using and more accurate and consistent coding are essential and present opportunities to reduce cost simply through strategies that target the reduction of non-elective admissions.

As for people with MS themselves, well planned services that provide intervention through sufficient provision of skilled clinicians are vital to their wellbeing. High quality, proactive care is needed to prevent many of the secondary complications of MS and to ensure that people with MS stay as well as they possibly can.

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Net Ingredient Cost data is taken from the GP Practice Prescribing Chemical-level Data provided by the Health and Social Care Information Centre (HSCIC) (www.hscic.gov.uk/prescribing).

2014/15 data are provisional and may be incomplete or contain errors for which no adjustments have yet been made. Counts produced from provisional data are likely to be lower than those generated for the same period in the final dataset. This shortfall will be most pronounced in the final month of the latest period, e.g. September from the April to September extract. It is also probable that clinical data are not complete, which may in particular affect the last two months of any given period. There may also be errors due to coding inconsistencies that have not yet been investigated and corrected.

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Key findings and recommendations

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Key messages

- In 2013/14 non-elective hospital admissions for people with multiple sclerosis in England cost the NHS £43 million.
- The most common reasons for non-elective admissions were infections, urinary tract and respiratory, pneumonia and MS itself (including MS relapse), many of which could be prevented with greater emphasis on anticipatory care.
- Non-elective care accounted for 46% of overall spend on care for people with MS in hospital, whilst accounting for only 27% of the total admissions, and therefore represents a large opportunity to reduce cost.
- Reducing the number of these non-elective hospital admissions would automatically reduce financial burden on the NHS and also make huge gains towards improving the health of people with MS.
- This could be achieved by identifying patients at risk and addressing the issues before onset of a crisis. MS nurse specialists are ideally placed to identify this group of patients and provide proactive care, also involving GPs, neurologists, allied health professionals (AHPs) and community services.
- Identifying the money currently spent on non-elective admissions could justify service investment, with CCGs reinvesting savings in the provision of more proactive care.

Findings summary and recommendations

Non-elective admissions for people with MS

- The number of non-elective (emergency) admissions of people with MS in England was 23,665 in 2013/14, relating to 14,960 unique individuals – 17% of the estimated 89,790 people with MS. Nearly 37% of emergency admissions (8,695) were therefore repeat admissions.
- The total number of non-elective admissions remained virtually flat between 2010/11 and 2013/14.
- Non-elective admissions for people with MS cost the NHS £43m in 2013/14, an average of £1,820 per admission. The admission cost was similar, regardless of whether MS was coded as a primary or secondary diagnosis for admission.

- The average length of stay of non-elective admissions was 7.7 days in 2013/14. There was an overall reduction of 5.2% in the number of bed days used between 2010/11 and 2013/14, in line with the fall in mean admission length across the NHS.

Elective admissions for people with MS

- The number of elective admissions of people with MS in England was 63,221 in 2013-14, of which the vast majority (52,846) were day cases.
- The number of elective admissions was up by 20,193 between 2010/11 and 2013/14, but this increase is fully accounted for by an increase in admission for the administration of immunomodulating drugs (MS disease modifying drugs) which increased by 150.21% (20,553 admissions) over this three year period. This reflects the transition to new therapies which are administered by IV infusion.*
- The average length of stay for elective admissions (excluding day cases) was 4.7 days in 2013/14. There was an overall reduction of 28% in the number of bed days used between 2010/11 and 2013/14.

**The data was obtained by analysing the number of patients that have been coded as having received an X893 (Immunomodulating drugs Band 1) OPCS code, whilst in the same episode of care being coded with a G35X (Multiple Sclerosis) ICD-10 code in any diagnosis position.*

Reasons for MS-related admissions

- The most common reasons for non-elective admissions in MS were bladder & bowel issues, MS itself (including MS relapse), and pneumonia / respiratory tract infections.
- Urinary tract infections accounted for 14% of emergency MS admissions (compared with only 3% of all population admissions) and cost an average of £2,556 per admission. The total cost for all bladder and bowel related MS admissions in 2013/14 was more than £11m.
- Respiratory issues accounted for more than £5.5m of non-elective MS admission costs in 2013/14. Whilst not all of these will be directly due to MS, this remains significant.

Geographic variation

- There is wide variation between Clinical Commissioning Groups (CCGs) nationally, and between CCGs within the same Strategic Clinical Network in terms of their admission rates and costs.

- Some of this variation will be explained by local variation in the prevalence of MS, but as there is currently no accurate record of MS prevalence across England, this cannot be analysed.
- Further variation in elective admissions may be explained by the difference in the way in which admissions for administration of disease modifying drugs are coded: in some places as a day case admission and in others as an outpatient.
- Nevertheless, the extent of variation across geographies suggests that some CCGs could be doing much more to address unscheduled care in MS.

Action needed

- Everyone with MS needs access to services to help them to manage their symptoms or disease, and to identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled care. MS specialist nurses, neuro-specialist allied health professionals and community rehabilitation teams are key elements of this service provision, and current shortfalls in many parts of the country need to be addressed.
- CCGs need to ensure that they have in place appropriate pathways for identifying and managing bladder problems in MS (particularly UTIs), and GPs have a key role to play in this.
- CCGs also need to have in place systems for ensuring that everyone with a diagnosis of MS is known to specialist services and has (as a minimum) the specialist annual review recommended by NICE, to identify MS-related problems and enable early intervention.
- CCGs should stratify the caseload of people with long-term neurological conditions, including MS, within their areas, to establish which patients are at most risk of multiple, lengthy and costly admissions, and focus preventative care on these individuals.
- Further work is needed to establish accurate local prevalence data for MS, which is essential for service commissioning / planning, ensuring that everyone with MS is in contact with specialist services, and for benchmarking performance between areas.
- More accurate and consistent coding, particularly of elective admissions in MS, would enable further and more accurate analysis of the size of the opportunity to improve care.

Introduction

This report is about hospital admissions of people with multiple sclerosis (pwMS) and the variation in performance between Clinical Commissioning Groups (CCGs) in England. The purpose of the report is to highlight MS admissions and the reasons they occur. The report will also demonstrate where there could be opportunities for reducing this activity and preventing admissions.

MS is a neurological condition affecting the central nervous system, usually causing some level of permanent disability to develop. There are three main types of MS (Lublin et al, 2014):

- **Relapsing remitting** - Distinct attacks of symptoms, followed by recovery, either fully or partially
- **Secondary progressive** - Relapsing remitting MS frequently becomes secondary progressive MS, with the gradual build-up of disability
- **Primary progressive** - Primary progressive MS develops over time, with no periods of recovery from symptoms and there is a gradual build-up of disability.

MS can affect anyone, although more women than men are affected, and globally it is more prevalent in higher income countries and those further away from the equator (WHO, 2008). While it is possible to be diagnosed at any age, relapsing remitting MS is typically diagnosed between the ages of 20 and 40 years and primary progressive MS is more often diagnosed between the ages of 30 and 50 (Harding et al., 2015).

The cause of MS is unknown, but a combination of genetic and environmental factors are thought to play a role (Franklin & Nelson, 2003). Treatment is aimed at minimising relapses and treating symptoms; currently there is no cure.

As with any long-term condition, pwMS may need to use hospital facilities at various stages during the course of the disease. MS is generally diagnosed and treated on an outpatient basis, but people may be admitted with acute symptoms of MS prior to diagnosis, which investigations will then confirm.

Common reasons for elective admissions in MS include the administration of intravenous disease modifying drugs (IV DMDs) and planned interventions relating to bladder and bowel management.

Emergency admissions in MS may occur as a result of the serious potential complications associated with MS. A recent observational study showed that as many as 80% of pwMS will be diagnosed with an infection after diagnosis (Jick et al., 2015) including urinary tract infections and respiratory infections, and that these are associated with additional mortality. These, and other causes of emergency admission such as constipation, falls and pressure ulcers can be often averted with the right level of early identification, intervention and support.

Like anyone, pwMS may also need to access hospital for other health issues like hypertension, diabetes, cancer or the need for elective surgery.

Whilst it is important to understand the reasons for hospital admission, the emphasis in this report is directed towards the identification of the reasons for emergency or non-elective admissions. This will assist both clinicians and commissioners in understanding how these might be reduced to improve outcomes in the care of pwMS and reduce costs to the NHS.

This report will be of primary importance to a number of health and social care professionals alongside commissioning groups. General practitioners (GPs), MS specialist nurses (MSSNs), neurologists and CCGs should understand where effective management of people with MS can be improved and how it will serve to enhance treatment and decrease the burden and cost to the NHS. It should also be noted that the reasons why pwMS are admitted to hospital are also not all necessarily appropriately coded and this needs to be recognised when interpreting the data.

For those not familiar with the terminology around hospital admissions and data it may be useful to read the glossary at the end of this report first. The rest of the report is structured as follows.

Section 1 explains how the report was produced and explains that, without reliable prevalence data for MS across the UK, we can only make an estimate of admissions and costs normalised per 1,000 people with MS.

Section 2 presents the overall trends in hospital admission numbers and costs between 2010/11 and 2013/14.

Section 3 looks at the reasons for admission in MS, focusing particularly on non-elective admissions, and highlights complications of MS that are generating particularly high levels of admissions and indicative cost.

Section 4 presents an overview of the variation between CCGs in admission rates and indicative costs for non-elective MS admissions. Because of the lack of local prevalence data, it is impossible to separate differences due to varying prevalence, to differences due to real admission rates for pwMS, and for this reason individual CCGs are not named.

Section 5 outlines variation between Strategic Clinical Networks.

Finally, following the conclusion a series of appendices present more information about the role of MS specialist nurses, urinary tract infections and respiratory infections in MS and a glossary of terms.

1. Methodology

1.1 Prevalence of MS

The prevalence of MS in the UK is uncertain and has been the subject of significant debate. However, the assumption used in this report is that 107,000 people had MS in the UK in 2012/13, of whom 87,686 were in England. This is the number given in a MS Society consensus report (MS Society, 2014) based on the results of a study by Mackenzie et al looking at GP registry data from 1990-2010 (Mackenzie et al., 2014) combined with an estimate that only 82% of the MS diagnoses mentioned in GP records were correct (MS Society, 2014). A further assumption made in this report is an average 2.4% increase in the prevalence of MS each year, due to increasing longevity, based on the Mackenzie study. Based on this, we have estimated the number of pwMS in England in 2013/4 (the year of most data presented in this report) as 89,790.

1.2 Sources of data

This report utilises Hospital Episode Statistics (HES) which is a cleaned and audited version of Secondary Uses Service (SUS). HES and SUS data start from the same source, the NHS Trusts episode of care data; this is all consolidated in the SUS warehouse from Patient Administration Systems (PAS). Extracts from the SUS warehouse, the raw input data, form HES data. SUS data is only available to the NHS as it contains patient identifiable data and clinician sensitive data. This can be accessed daily by the Trust. HES data is still available at patient record level but the identifiable fields have been pseudonymised.

HES contains around 1 billion records of patients who have been treated in hospital trusts in England. This includes inpatient, outpatient, A&E and critical care activity. The inpatient data splits out elective activity (planned care) and non-elective (non-planned care).
All hospital activity is recorded but not always as accurately as it could be. Inpatient activity is recorded by ICD-10 code (International Classification of Diseases Version 10) and Office of Population Censuses & Surveys, classification of procedures and interventions version 4 (OPCS-4). Code and outpatient activity is recorded as either a first outpatient or follow up appointment. It should be noted that outpatient procedures are also coded.

ICD-10 codes are used to classify diseases and other health problems in secondary care. Patients can have both a primary and secondary diagnosis (up to 20). Primary diagnosis is the main condition treated or investigated during the relevant episode of healthcare (reason for admission does not constitute primary diagnosis). Secondary diagnoses are defined as conditions or complaints either coexisting with the primary diagnosis or arising during the episode of patient care. The provider will enter only the number of codes necessary to describe and manage the patient's condition.

MS has the ICD10 code 'G35' and the information within this report refers to patients that have this code in either the primary or a secondary diagnosis position.

To protect the privacy and confidentiality of individuals, suppression has been applied to the HES data; '*' represents a figure between 1 and 5, '**' indicates that secondary suppression has been applied to prevent the calculation of a number between 1 and 5. This is in line with the data reuse licence issued by the Health and Social Care Information Centre.

1.3 Inconsistencies in coding

All NHS providers and private providers (if they carry out NHS work) have to submit their activity data on a monthly basis (they do not get paid otherwise).The quality of the data recorded may vary from trust to trust. The type of admission recorded for the same treatment may also differ between provider units, for example in some areas the administration of IV disease modifying drugs may be coded as an outpatient procedure whilst in other hospitals the therapy is recorded as a day case. There is a drive and need for more consistency when coding data (Capita, 2014).

1.4 Limitations of data

There are also limitations caused by lack of detail in the admission record. For example a person may be admitted to hospital with a general MS diagnosis code when the specific reason for that admission may be an MS relapse. Again a more consistent approach to recording patients would be useful and would enable providers to get paid correctly for the service they deliver.

1.5 How data is presented in this report

Where MS is in any diagnosis position, admissions have been split by elective and non-elective admissions. MS activity has been presented for every 1,000 people with MS (based on the estimated prevalence discussed in section 1.1) enabling comparison between organisations.

The mean number of bed days for MS hospital admissions is used to determine the indicative cost of treating MS in the NHS. Day patient admissions (day cases) are not included in this analysis as they do not have an overnight stay so are not applicable.

The total indicative cost and admissions for MS are used to determine the average indicative cost of admissions for pwMS. If a patient has another diagnosis as well as MS this is called a comorbidity. The most common comorbidities in people with MS were gathered from HES data set and normalised per 1,000 people. Ethical approval was not required as this work was deemed service evaluation due to the suppression of small numbers.

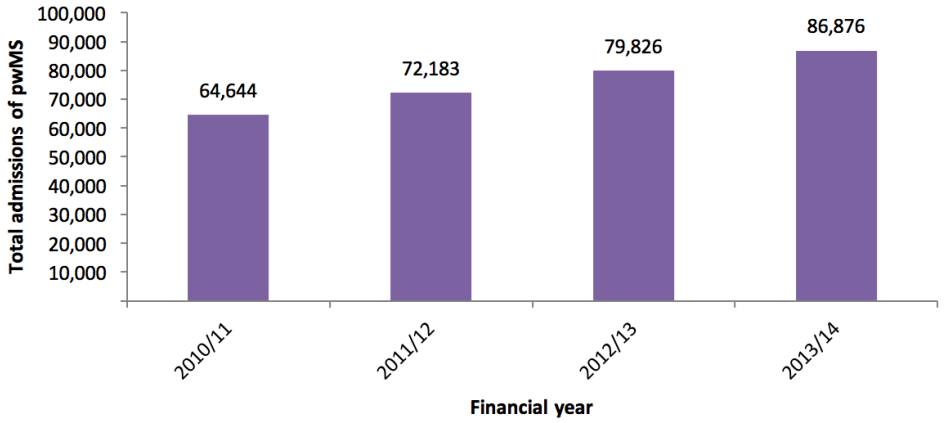
2. Overall trends in hospital admissions in MS

The four year trend in MS hospital admissions is split into non-elective admissions, elective admissions (excluding day cases) and elective admissions (including day cases).

2.1 Total number of admissions with an MS diagnosis

HES data shows that over the last four years there was a consistent increase in the number of admissions for pwMS year on year (Fig. 1).

Figure 1
Total number of admissions of people with MS per financial year 2010/11 to 2013/14



The number of admissions per 1,000 pwMS also shows an overall increase, but to a lesser extent (Fig. 2).

Breaking this down into type of admission (Fig. 3), normalised per 1,000 people with MS, shows that whilst elective admissions grew by an average of 11% per annum over the three years, the number of non-elective admissions grew by only 0.6% per annum over the same period.

Further analysis shows that the increase in elective admissions over the three years (an additional 20,193 admissions) is more than accounted for by the increase in admissions for immunomodulating drugs (DMDs) over the same time period (an additional 20,553 admissions). Excluding admissions for DMDs, other elective admissions for people with MS have fallen slightly over the period.

Figure 2
Number of admissions of pwMS per 1,000 people with MS 2010/11 to 2013/14

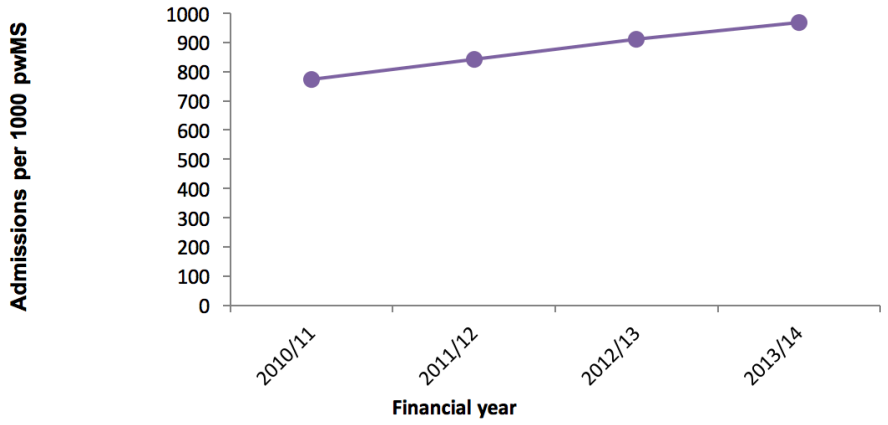
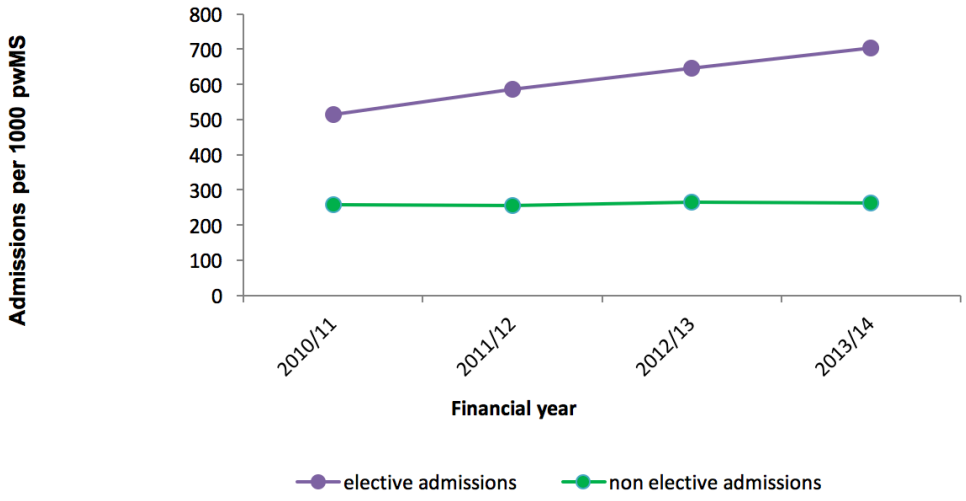


Figure 3
Number of elective and non-elective admissions of pwMS per 1,000 people with MS 2010/11 to 2013/14



2.2 Total unique patients admitted at least once

In 2013/14 there were 86,876 MS coded admissions into hospital but these admissions were related to 29,808 unique individuals (33% of the estimated people with MS), meaning that some pwMS were admitted more than once. Over the year, 17% of the estimated people with MS were admitted non-electively, an average of 1.6 times each in the year.

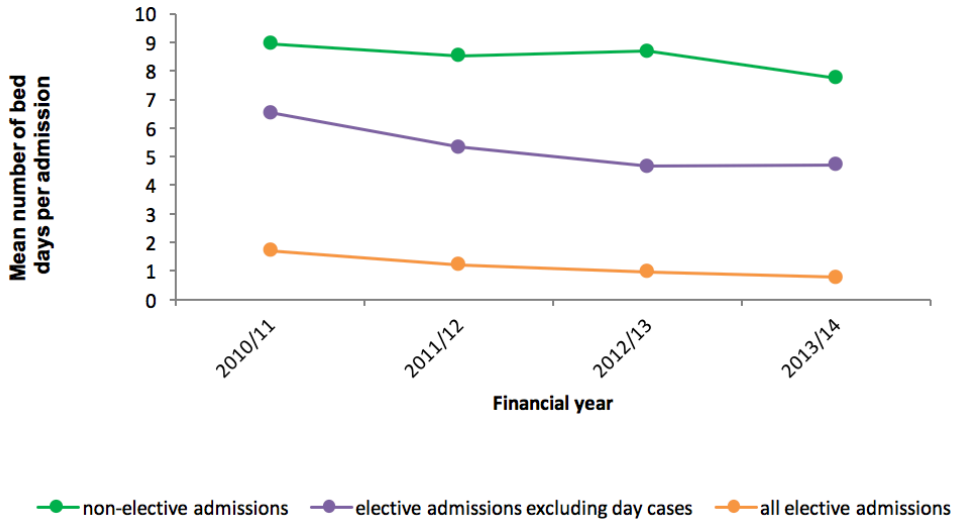
Table 1
Admission count and unique patients in 2013/14

Admission type	Admission count	Unique individuals with MS	Unique individuals admitted as % of all people with MS
Non-elective	23,655	14,960	17%
Elective	63,221	19,227	21%
Elective (excluding day cases)	10,375	6,858	8%
Total	**86,876**	**29,808**	**33%**

2.3 Length of hospital stay

On average, non-elective admissions are longer than elective admissions (Fig. 4).

Figure 4
Mean number of bed days per admission of a person with MS, for elective admissions, non-elective admissions and elective admissions excluding day cases 2010/11 to 2013/14



2.3.1 Non-elective admissions

There was a 13% reduction in mean length of stay (Fig. 4) over three years, resulting in a 5.2% reduction in overall non-elective bed days. The average length of stay for non-elective admissions in 2013/14 was 7.7 days.

2.3.2 Elective admissions

The mean length of hospital stay has reduced over the four year period by 54%, with a consistent 20–30% reduction in the mean number of bed days per elective admission each year (Fig. 4).

A large reason for this is an increase in the number of day case elective admissions. However, when these day cases are excluded from elective admissions there is still a reduction (28%) in the mean number of bed days per elective admission (Fig. 4). The average length of stay for elective admissions (excluding day cases) in 2013/14 was 4.7 days.

2.4 Overall costs of MS admissions

Table 2
Admission costs for 2013/14

Admission type	Total cost	Avg cost per admission
Non-elective	£43,051,255	£1,820
All elective	£50,433,857	£798
Day case	£31,578,576	£598
Elective (excluding day cases)	£18,855,281	£1,819

- The total estimated cost of inpatient hospital care for non-elective patients with MS in 2013/14 in England was £43,051,255
- Non-elective care accounted for 46% of overall spend on care for people with MS in hospital, whilst accounting for only 27% of the total admissions, and therefore represent a large opportunity to reduce cost
- The total estimated cost of elective inpatient hospital care for people with MS (excluding day cases) in 2013/14 in England was £18,855,281.
- The costs will include drugs administered in hospital but not high cost drugs like disease modifying drugs which are reimbursed separately. The cost of these drugs is generally negotiated locally by each provider. The costs will also not include any FP10 prescriptions written by consultants for dispensing for community use that arise as a result of any hospital activity. An FP10 prescription is a prescription written by a doctor, nurse or pharmacist prescriber for medication a person will take at home.
- Non-elective hospital admissions on average cost slightly more than elective hospital admissions (excluding day cases) (Fig. 5). This is true for all hospital admissions, MS or otherwise. The costs for non-elective admissions for people with MS are very similar regardless of whether MS is coded as a primary or secondary diagnosis (Fig. 6).

Figure 5
Mean cost of elective and non-elective admissions for all hospital patients and all admissions for people with MS.

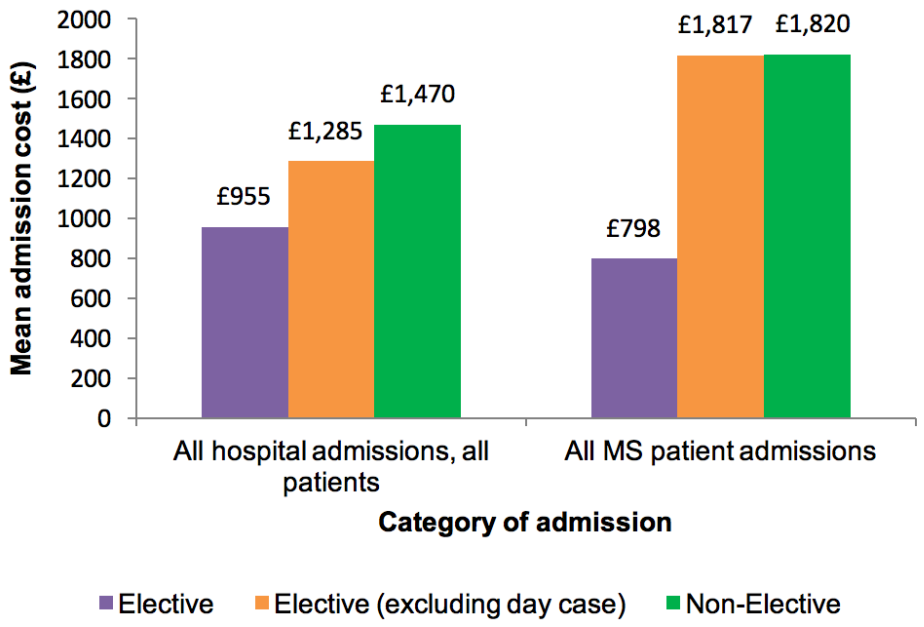
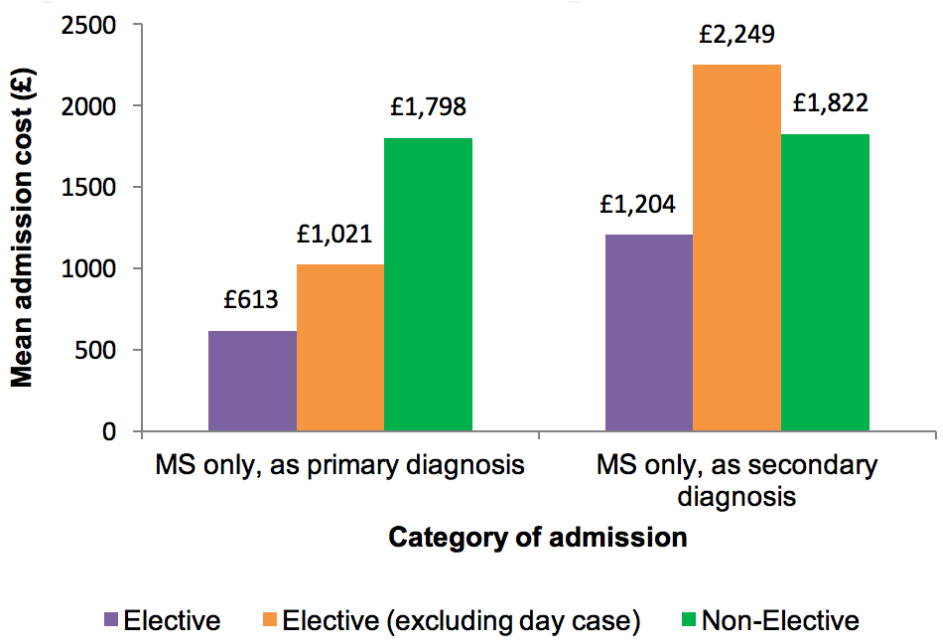


Figure 6
Mean cost of elective and non-elective admissions where MS is a primary or secondary diagnosis.



3. Reasons for admissions in MS

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3.1 Non-elective admissions

Non-elective or unplanned hospital admissions in MS are costly both to the NHS and to pwMS (in terms of distress and quality of life). In order to proactively prevent these admissions it is important to know which diagnoses are most common. The 10 most common primary diagnoses for non-elective admissions of pwMS in 2013/14 were:

- Urinary tract infection
- Multiple sclerosis
- Lobar pneumonia, unspecified
- Pneumonitis due to food and vomit
- Unspecified acute lower respiratory infection
- Mechanical complication of urinary (indwelling) catheter
- Pneumonia, unspecified
- Constipation
- Cellulitis of other parts of limb
- Sepsis, unspecified

These primary diagnoses are all significantly more prevalent in people with MS than in equivalent admissions from the general population during the same time period (Table 3).

Table 3
Percentage of MS non-elective admissions and whole population non-elective admissions that are the result of the most prevalent primary diagnoses in pwMS.

Primary reason for admission	% of MS non-elective admissions	% of whole population non-elective admissions
Urinary tract infection	14.1	2.9
Multiple sclerosis	10.2	0.04
Lobar pneumonia, unspecified	3.1	2
Pneumonitis due to food and vomit	3.0	0.2
Unspecified acute lower respiratory infection	2.9	1.6
Mechanical complication of urinary (indwelling) catheter	1.9	0.16
Pneumonia, unspecified	1.7	1.1
Constipation	1.6	0.85
Cellulitis of other parts of limb	1.4	0.98
Sepsis, unspecified	1.3	0.58

3.2 Elective admissions

While non-elective admissions are more costly, it is important to remember that elective admissions occur more frequently so have a significant overall impact on costs. We need to recognise that patients attending hospital for IV DMDs will be coded as an elective day case admission. Guidance is clear on this and it is important that coding is consistent across the NHS to reflect this. See here for guidance on type of procedures that should be classified as a day case admission: http://systems.hscic.gov.uk/data/nhsdmds/faqs/cds/admitpat/daycase (Capita, 2014).

The 10 most common primary diagnoses in pwMS for elective hospital admissions in 2013/14 were:

- MS
- Other specified disorders of bladder
- Fitting and adjustment of urinary device
- Adjustment and management of infusion pump
- Neuromuscular dysfunction of bladder, unspecified
- Malignant neoplasm: Breast, unspecified
- Cataract, unspecified
- Calculus in bladder
- Low back pain
- Attention to cystostomy

Again, these primary diagnoses are more prevalent in pwMS than in equivalent admissions from the general population during the same time period, except for admissions for cataracts and breast cancer (Table 4).

Table 4
Percentage of MS elective admissions and whole population elective admissions that are the result of the most prevalent primary diagnoses in people with MS.

Primary reason for admission	% of elective MS admissions	% of whole population elective admissions
MS	68.5	0.43
Other specified disorders of bladder	1.15	0.26
Fitting and adjustment of urinary device	0.86	0.36
Adjustment & management of infusion pump	0.75	0.05
Neuromuscular dysfunction of bladder, unspecified	0.69	0.03
Malifnant neoplasm: Breast, unspecified	0.59	1.21
Cataract, unspecified	0.56	2.12
Calculus in bladder	0.48	0.05
Low back pain	0.42	0.66
Attention to cystostomy	0.36	0.02

3.3 MS admission costs

It is useful to understand how much hospital admissions cost CCGs in order to ensure cost efficiencies can be made to encourage investment in preventative services. The 10 most costly primary diagnoses of admissions for pwMS in 2013/14 were:

- MS
- Urinary tract infection
- Pneumonitis due to food and vomit
- Fracture of neck of femur
- Lobar pneumonia, unspecified
- Unspecified acute lower respiratory infection
- Constipation
- Gonarthrosis, unspecified
- Pneumonia, unspecified
- Gastroenteritis and colitis of unspecified origin

While the cost of these admissions comprises both elective and non-elective admissions, it is interesting to note that for eight of the diagnoses over 80% of the total cost is from non-elective admissions. Furthermore, seven of these eight feature in the list of the 10 most common diagnoses for non-elective admissions, and the percentage cost for these are more for pwMS than for that of the general hospital population (Table 5).

Table 5
Percentage cost of MS and whole population admissions

Primary reason for admission	% cost of MS admissions	% cost of whole population admissions	Average cost per admission
MS	33.1	0.17	£682
Urinary tract infection	9.6	2.0	£2,555
Pneumonitis due to food & vomit	1.6	0.17	£2,465
Fracture of neck of femur	1.3	1.56	£5,462
Lobar pneumonia, unspecified	1.3	0.88	£1,593
Unspecified acute lower respiratory infection	1.0	0.57	£1,415
Constipation	0.9	0.38	£1,711
Gonarthrosis, unspecified	0.8	2.5	£4,910
Pneumonia, unspecified	0.7	0.49	£1,729
Gastroenteritis and colities of unspecified origin	0.7	0.77	£2,121

3.4 Priority areas for admission prevention

There are two ways of reducing admissions costs – either reduce the number of patients who need hospital care, or reduce the costs associated with the most expensive types of admission diagnoses. Since there is a large overlap in MS between the most expensive diagnoses and the most common ones, reducing the number of admissions would automatically reduce the cost.

Proactive care involving GPs, neurologists, MS specialist nurses and CCGs which identifies patients at risk and addresses issues before the onset of a crisis when hospital admission is required, will serve to reduce the financial burden on the NHS and also make huge gains towards improving the health of people with MS. The data suggests that there are three main areas where it may be possible to reduce admission costs for pwMS.

3.4.1 Management of bladder and bowel related comorbidities

There is a clear trend in complications related to the bladder and bowel in both elective and non-elective admissions. These include emergency admission for urinary tract infections and constipation, and routine admissions for fitting urinary devices, bladder dysfunction and bladder calculus. Together these issues cost the NHS over £11m in 2013/14, of which more than £9m was for unscheduled care (Table 6).

This serves to highlight the need of effective bladder and bowel management in people with MS. Appendix ii of this report gives more information about this.

Table 6
Costs relating to bladder and bowel comorbidities in people with MS

Comorbid groups	Elective costs	Non-elective costs	Total costs
Bladder Conditions (N31 - N33)	£705,613	£59,628	£765,241
Urinary Tract Condition - inc UTI (N34 - N39)	£531,187	£8,780,987	£9,312,174
IBS and Constipation (K58 - K59)	£175,532	£807,453	£982,986
Faecal Incontinence (R15)	£57,560	£7,066	£64,625
Total	**£1,469,892**	**£9,655,134**	**£11,125,026**

3.4.2 MS relapse

'MS' is the most costly diagnosis code for admissions of people with the condition. 'MS' itself is given as the primary diagnosis code in over 10% of non-elective admissions for pwMS (Table 3) and this will include management of MS relapses.

Relapses are potentially treatable in the community with the right care, but may result in a hospital admission if the person with MS becomes unable to cope at home or is so unwell that IV steroids are required. Data published by the SWIMS study (a cohort study of people with MS in the South West of England) found that 11% of relapses resulted in a hospital admission (Zajicek et al., 2010).

Where MS specialist nurses (MSSNs) have manageable caseloads and appropriate protocols in place, including responsive helplines, they can offer this care - providing the information, steroid treatment (where indicated), monitoring and support that someone going through MS relapse may need. They can then refer patients for admission if inpatient care is needed, as a last resort. The MS Trust will be publishing a new consensus guide to the management of relapse in MS, including a guide to auditing the effectiveness of services, in early 2016.

3.4.3 Respiratory complications

Respiratory problems are a frequent complication of more advanced MS, for reasons that are described in Appendix iii. The overall cost of non-elective admissions for pwMS for respiratory conditions in 2013/14 was over £5m, of which more than £2m was for pneumonia or influenza (ICD codes J09 – J18). Whilst not all of these admissions will have been MS-related (people with MS may of course have pre-existing conditions such as asthma and occupational or smoking related lung disease), this cost points to another area where intensive prevention may have averted some cost. The costs associated with most common respiratory related MS admissions are shown in Table 7.

ICD-10 Subchapter	Elective	Non-elective	Grand Total
Respiratory Conditions (J00-J99)	£511,040	£5,007,643	£5,518,683
Influenza and pneumonia (J09-J18)	£106,981	£1,902,825	£2,009,806
Lung diseases due to external agents (J60-J70)	£99,513	£1,460,205	£1,559,718
Other acute lower respiratory infections (J20-J22)	£40,154	£929,463	£969,618

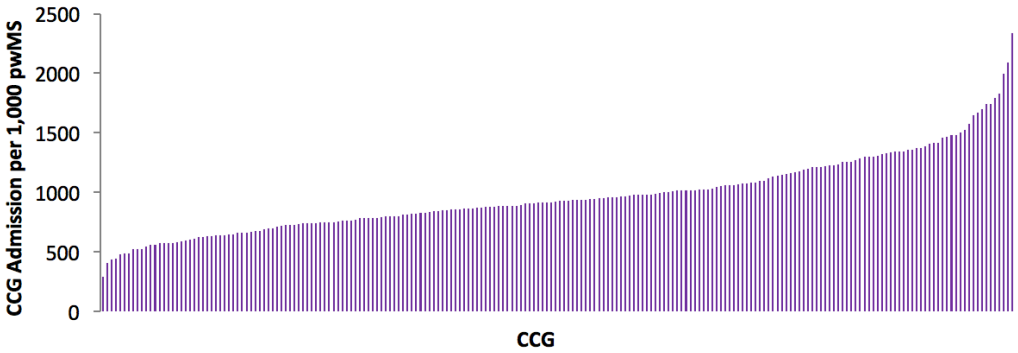
Table 7
Costs relating to respiratory comorbidities in people with MS

ICD-10 Code	Elective	Non-elective	Grand Total
J690 - Pneumonitis due to food & vomit	£99,513	£1,432,772	£1,532,285
J181 - Loar pneumonia-unspecified	£58,681	£1,147,562	£1,206,243
J22X – Unspecified acute lower respiratory infection	£39,641	£911,044	£950,684
J189 - Pneumonia- unspecified	£36,255	£645,436	£681,691
J440 - Chronic obstructive pulmonary disease with acute lower respiratory infection	£4,371	£250,954	£255,325
J90X – Pleural effusion, not elsewhere classified	£29,316	£59,960	£89,276
J441 - Chronic obstructive pulmonary disease with acute exacerbation, unspecified	£8,607	£64,266	£72,873
J459 - Asthma, unspecified	£2,303	£62,922	£65,226
J180 - Bronchopneumonia, unspecifed	£6,014	£54,969	£60,983
J969 - Respiratory failure, unspecified	£812	£57,137	£57,949

4. Variation between CCGs

Clinical commissioning groups (CCGs) are clinically led NHS England bodies which are responsible for the commissioning of a large proportion of local healthcare services within the NHS.

Figure 7
Number of admissions per 1,000 people with MS by CCG in 2013/14.



This chapter focuses on non-elective admissions by CCG, because these are likely to be most amenable to prevention in MS.

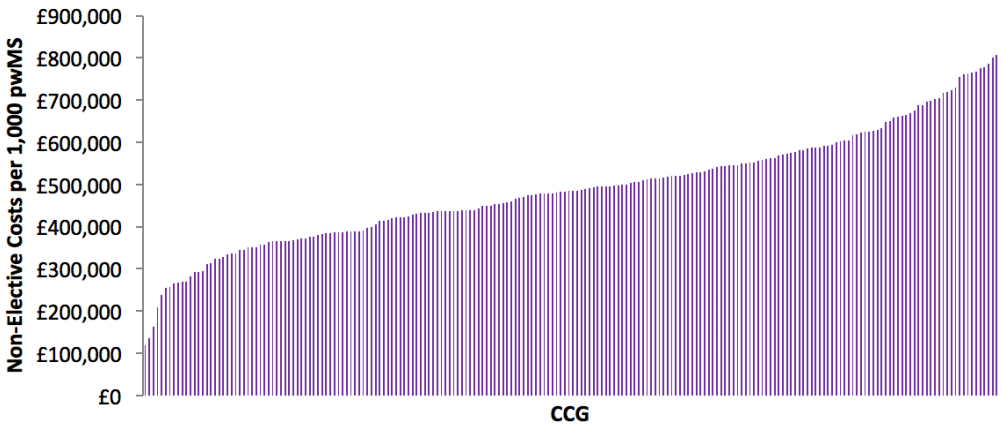
There is a natural variation in the prevalence of MS across CCGs and geographical regions. There is as much as a 50% difference in the prevalence of MS between the 10 administrative regions of the England (Mackenzie et al., 2014). Because there is no accurate MS prevalence data, it is impossible to say whether a high rate of non-elective admissions in a CCG is due to a high MS prevalence rate or real differences in the admission rate for pwMS. However, if a CCG has a particularly large number of non-elective admissions, or their admissions are particularly expensive, it may be that there are specific issues that need addressing.

Figure 7 shows the number of admissions per (estimated) 1,000 per people with MS by CCG and shows a six fold variation between the lowest and highest.

Figure 8 looks at costs per non-elective admission per CCG and again shows wide variation. The HES data cost analysis uses standard NHS tariff costs for healthcare resource groups. This means variations in cost may be due to differences in diagnostic codes rather than differences in actual costs of providing the same care across CCGs. Investigating the highest cost CCGs reveals that the mean cost of non-elective admissions could be being dramatically increased by a small number of expensive admissions. Through appropriate risk stratification and case finding, these costs could be more appropriately managed.

- The mean cost of a non-elective admission for a person with MS in 2013/14 was £1,820, but between CCGs this ranges from £1,042 to £2,861 (Fig. 8).
- For comparison, the mean cost of all non-elective hospital admissions for the general population in 2013/14 was £1,470 (Fig. 5).

Figure 8
Mean cost per non-elective admission (£) for a person with MS in 2013/14.



5. Variation between Strategic Clinical Networks

"Strategic Clinical Networks [SCNs] bring together those who use, provide and commission services to make improvements in outcomes for complex patient pathways using an integrated, whole system approach."

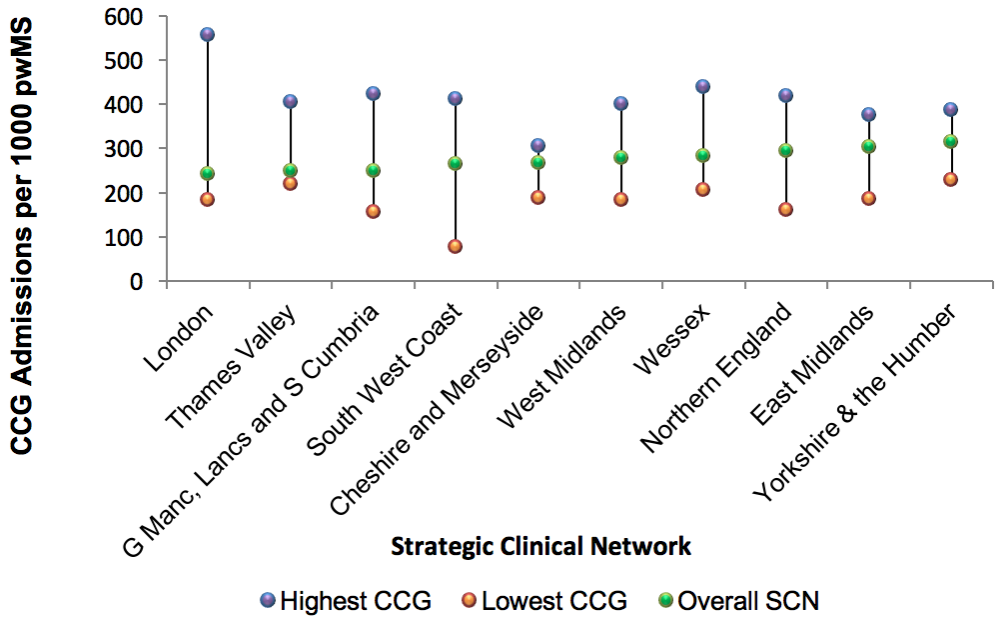
NHS England, 2015: www.england.nhs.uk/ourwork/part-rel/scn/

There are 12 SCNs in England. SCNs are aiming to provide relatively uniform care pathways between CCGs within an SCN, but have only been in existence since 2013 and are still working towards this aim.

Figure 9 below shows the average number of non-elective admissions for people with MS per SCN, and includes the variation between the highest and lowest CCG within the SCN. Although SCNs have not been in existence for a long period of time some organisations are performing better than others in minimising variation in non-elective hospital admissions of pwMS. However this may not just be due to better management.

There are a number of other factors the primary one being that the prevalence of MS in each region of England is variable (Mackenzie et al., 2014). As discussed in the previous chapter, differences in admission number may be as much to do with prevalence variation as true differences in admission number. This discrepancy in local prevalence could go at least some way to explaining the differences between CCGs and SCNs which we cannot account for.

Figure 9
Average rate of non-elective admissions for people with MS per SCN in 2013/14.



Conclusion

Several factors are key to delivering better, more cost effective care to pwMS.

First, we need a better understanding of the prevalence of MS both nationally and locally at CCG level. This is crucial because it will allow CCGs to better plan the services they commission and measure their performance (admission rates and level of spending) against other CCGs. Accurate prevalence data is also essential to ensure that everyone with MS in a given area is accessing specialist MS services, and having (as a minimum) the specialist MS annual review recommended by NICE (NICE, 2014).

Part of planning better services for pwMS also relies on improving the admissions data that CCGs are using and more accurate and consistent coding is key to this. While non-elective admissions are more costly, elective admissions occur more frequently so have a significant overall impact on costs. The process must be standardised throughout the NHS to gain a better understanding of data with regards to elective admissions and outpatients.

With accurate data at their fingertips, CCGs can make much needed improvements to services by case finding and risk stratification of those people with MS most at risk of admission. Data can also be used to benchmark services between CCGs to consider how collaborative commissioning can support better care models.

Above all this report clearly points to areas where improvements in care are needed to prevent secondary complications of MS. The high numbers of people with MS admitted with bladder and bowel problems, MS relapse and respiratory infections highlight the need for more early intervention and the provision of preventative treatment. This requires sufficient provision of skilled specialist expertise from MS specialist nurses, neuro-specialist allied health professionals and community rehabilitation teams, amongst others. These largely preventable reasons for admission should be addressed as a priority through the provision of high quality, proactive care.

Appendices

i. MS specialist nurses

MS specialist nurses (MSSNs) have a vital role to play in the care of people with MS. The role of an MSSN is varied (Mynors et al., 2015), but includes:

- Information and psychological support, primarily at diagnosis
- When disease modifying drugs are prescribed – including decision making, training on administration and ongoing monitoring
- Monitoring and provision of symptomatic treatment and advice when the condition changes
- Coordinating care, particularly when care needs become complex.

Patients with access to MSSNs experience enormously improved care; however, access to MSSNs is not always available and their caseloads are hugely variable. It is clear that more MSSNs are needed to ensure sustainable caseloads (Mynors & Bowen, 2014).

The benefits of MSSNs, both financially and for patient care, increasingly need to be proved in order to secure NHS funding. Key quantifiable benefits of MSSNs are the cost savings they make by reducing hospital admissions – especially non-elective ones.

In preparing this report, we tested whether the level of MSSN provision has an effect on non-elective hospital admissions. We did this using the categories within the Case for Equitable Provision report (Mynors & Bowen, 2014) where there are estimates of the adequacy of provision of MSSNs – red, amber and green. We found no significant difference between the three groups in terms of non-elective hospital admissions for people with MS.

There may be several reasons why no association between MSSN availability and emergency admissions was found. First, prevalence of MS within individual CCGs varies significantly and is currently unknown, as already discussed. Therefore the emergency admission rates 'per 1,000 people with MS' may be significantly under- or over-stated. Areas with higher prevalence will naturally have higher levels of emergency admissions. Secondly, many other factors besides MS nurse availability will inevitably impact on admission rates, including availability of emergency respite and community care to avert admissions.

Data published by the MS Trust GEMSS programme (Mynors et al, 2015) provides evidence of the range of ways in which MSSNs in conjunction with the wider multi-disciplinary team improve outcomes for people with MS and save costs within the wider healthcare system.

ii. Urinary tract infections in MS

Urinary tract infections (UTIs) are very common in the general population (Foxman, 2002), but only 2.9% of non-elective hospital admissions in the 2013/14 HES data were due to a UTI. Amongst people with MS specifically however the percentage was 14.1%. This is worryingly high, especially given that infections of all types often exacerbate MS symptoms and could exacerbate relapse in relapsing remitting MS (Rakusa et al., 2013).

A common cause of urinary infections in MS is stagnant urine due to urinary retention. Measures which can prevent UTIs include ensuring enough fluid intake, avoiding constipation and practising intermittent self-catheterisation (ISC) if necessary (although catheterisation itself can also increase the risk of UTI) (NICE, 2012). MS specialist nurses and continence advisors are well placed to advise pwMS on measures they can take to reduce their risk.

When they do occur, UTIs should be treatable in primary care if diagnosed early enough, but for many people with MS this does not appear to be happening. There are a number of possible reasons that UTIs in people with MS may not be diagnosed promptly including that the symptoms of a UTI can be the same as the symptoms of MS, and people with MS being more susceptible to developing UTIs, due to bladder dysfunction (Rakusa et al., 2013).

The process to diagnose a UTI is based on three main aspects – symptoms, the results of an initial urine test, subsequent microbacteriological testing, and history of UTIs. Symptoms are the reason that most people visit a health practitioner and the usual way of diagnosing a UTI, but in people with MS the symptoms of a UTI are very similar to the symptoms of MS. This overlap could lead both pwMS and health practitioners to believe that the symptoms are due to MS, not a UTI, and thus delay a correct diagnosis.

In pwMS, infections can exacerbate the condition so prompt diagnosis and treatment can help (Fowler et al., 2009). For this reason it would seem that regular testing for UTIs would be recommended, but a recent report of MS experts by Fowler et al. (2009) indicated that testing for UTIs should not be routine (Fowler et al., 2009). By the nature of catheterisation, patients who catheterise are highly likely to test positive for a UTI on a dipstick, but very few will in fact have a UTI – regular testing of these patients therefore is not likely to be helpful (Rakusa et al., 2013; Fowler et al., 2009).

Many people with MS do not catheterise though and these patients also develop UTIs; regular testing of these patients using dipsticks could be an effective way to detect UTIs early in this subset of people with MS. The main problem with regular dipstick testing is the false positive rate – not all positive dipstick tests are the result of a UTI, asymptomatic or otherwise (Rakusa et al., 2013). An alternative to regular urine testing for UTIs could be improved education of people with MS and their GPs. If pwMS are aware that their symptoms may not be their MS, but a UTI, they can ensure that they are appropriately tested for a UTI, and not just assume that it is their MS.

Early detection, and therefore treatment, of UTIs would benefit patients by reducing the number of times they are admitted to hospital, but also hopefully reduce the exacerbation of their MS symptoms. CCGs, hospitals and the NHS budget will also benefit as treatment in primary care is cheaper than in hospital and this would reduce the strain on hospital beds.

iii. Respiratory infections in MS

Respiratory infections are one of the leading causes of death in pwMS and are cited as the primary cause of death on 47.5% of death certificates for people with MS (Hirst et al., 2007). These infections typically occur as a result of complications arising from reduced mobility and aspiration secondary to dysphagia (difficulty swallowing).

The prevalence of dysphagia in MS is uncertain although a 1997 study (Abraham et al., 1997) found that 43% of people with MS (N=525) had symptoms of dysphagia and reported that it was associated with higher levels of disability as measured by the EDSS. A more recent study (N=101) reported a prevalence of 31.7% amongst their study population.

We can say with some certainty that prevalence is greater than 30% and that dysphagia is consistently associated with higher EDSS scores and with brain stem signs (Prosiegel et al., 2004).

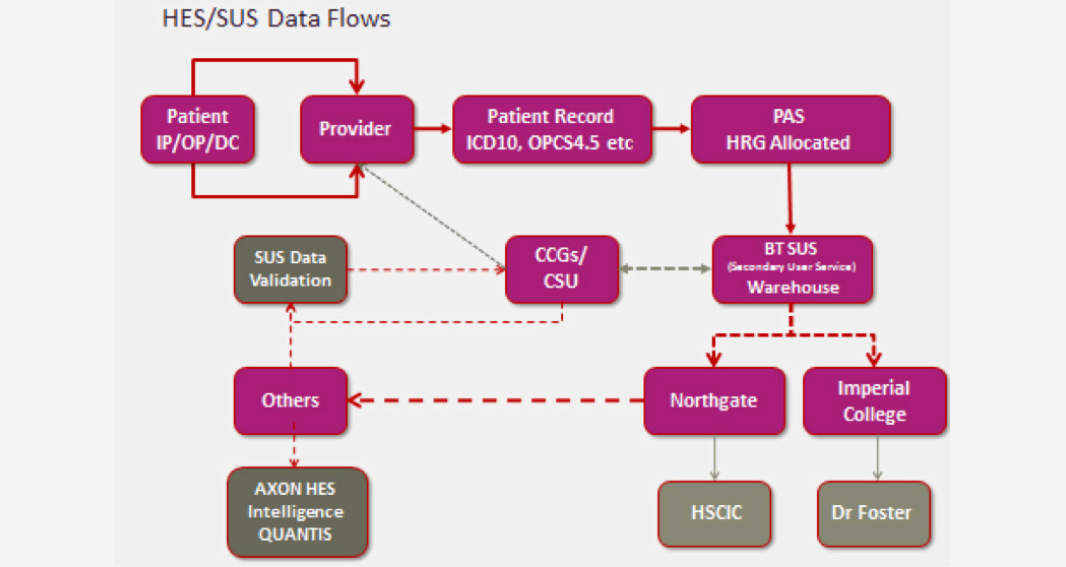
Whilst aspiration pneumonia due to dysphagia is not completely preventable there is much that can be done to minimise the risks and to make life much easier for people living with it. A thorough assessment by a speech and language therapist as soon as the first symptoms are reported is important. Subsequent regular assessments should be undertaken to ensure that any changes can be implemented as symptoms develop.

There are many quite straightforward interventions which can be used to reduce the risks of aspiration. These include lifestyle changes such as eating a modified diet, drinking thickened fluids, timing meals for periods when fatigue is less and ensuring an upright posture with support to maintain optimum head and neck alignment to facilitate swallowing. Anticholinergic medications can also be useful to reduce salivary secretions if this should become an issue (Prosiegel et al., 2004). In people with more severe problems insertion of a percutaneous endoscopic gastrostomy (PEG) tube may be used to further reduce the risk of aspiration from food and drink and maintain hydration and nutrition.

Poor mobility and intercostal muscle weakness may also increase an individual's risk of developing respiratory infections. One study of ambulatory people with MS (N=38) showed a decrease in respiratory function is associated with higher levels of disability in MS as measured by EDSS (Mutluay et al., 2005). An earlier study (Smeltzer et al., 1988) found that marked expiratory weakness develops in people severely disabled with MS and that respiratory function worsens as the upper extremities become increasingly involved. Assessment and intervention by specialist physiotherapists and occupational therapists can help to optimise respiratory function and reduce the risk of infection. For example the use of equipment to facilitate good posture when seated or lying, the use of standing frames and breathing exercises can all be helpful. Patient and carer education on the signs and symptoms of infection and the importance of early medical intervention should infection develop will also help to reduce their impact.

Glossary

How data is collected



Data abbreviations

HES	Hospital Episode Statistics
SUS	Secondary Uses Service
FCE	Finished Consultant Episode
ICD-10	International Classification of Diseases–Version 10
HRG	Healthcare Resource Group
OPCS	Office of Population Censuses & Surveys, classification of procedures and interventions

Inpatient data (actuals)

Inpatient admissions

Within Hospital Episode Statistics (HES), each inpatient episode has one primary diagnosis and up to 19 secondary diagnosis codes, HES records currently use the tenth revision of the International Statistical Classification of Diseases, Injuries and Causes of Death (ICD-10). Costs have been calculated using the Secondary User Service (SUS) generated Core Spell HRG code and applying the Payment by Results (PbR) tariffs, available at: https://www.gov.uk/government/collections/paymentby- results-pbr-in-the-nhs

Account has been taken of the adjustments to tariff that apply to long stays over trim point, day case admissions and emergency short stays for adults aged 19 and over. In addition, a Market Forces Factor (MFF) has been applied depending on the provider code. No top-up has been applied for specialised services best practice tariffs have not been applied.

Inpatient admissions & cost data – split by primary/secondary diagnosis and admission method

This presents inpatient admissions and costs (as above) but split by whether MS appears as either a primary or secondary diagnosis and by the method of admission (i.e. elective or non-elective).

Please note that if you add together the admissions for primary and secondary diagnosis codes you may end up with a higher figure than that listed in the headline inpatient admissions and costs. This is because the same ICD10 code may appear as both a primary and secondary diagnosis within the same admission – it will therefore be counted twice when the data is split by primary/secondary diagnosis).

Inpatient admissions & cost data – split by primary/secondary diagnosis

This data table presents inpatient admissions and costs, split by whether the neurological condition appears as either a primary or secondary diagnosis.
Please note that if you add together the admissions for primary and secondary diagnosis codes you may end up with a higher figure than that listed in the headline inpatient admissions and costs. This is because the same ICD10 code may appear as both a primary and secondary diagnosis within the same admission – it will therefore be counted twice when the data is split by primary/secondary diagnosis).

Inpatient admissions & cost data – split by admission method

This data table presents inpatient admissions and costs, split by the method of admission to hospital.

Inpatient admissions – length of stay

Mean Length of Stay (MLOS) is the total number of bed days within the year for a particular neurological condition divided by the number of admission for that same neurological condition. Please note that MLOS is not included in the normalised datasets because it already provides an average measure that is comparable across different sized geographies.

Excess bed days

Excess bed days is a count of the total number of bed days in hospital above 'trimpoint' – a set number of days as defined in the Payment by Results (PbR) tariffs for each HRG code. For most HRG codes, an additional cost is applied for each day spent in hospital above trimpoint – this data has been aggregated and is presented in the data table as the cost of excess bed days.

Zero day admissions

A zero day admission is defined as any non-elective admission where the total length of stay for the spell is zero days.

Re-admissions

A readmission is defined as follows:

- is unplanned/non-elective
- starts within 28 days of the end of another admission (where both admissions relate to the same patient)
- has a diagnosis (in any position) which is the same as the preceding admission's primary diagnosis (to indicate the two admissions relate to the same condition)
- relates to a patient who is over 18 years of age
- does not have a diagnosis which would be expected to cause a readmission (e.g. cancer).

Inpatient data (normalised)

Normalised data is simply the actual figures weighted by the size of the patient population, thereby allowing easy comparisons to be made between different sized geographies. Figures are presented per 1,000 patient population – i.e. it displays what the number of admissions would be if the size of the population was 1,000 patients.

Normalised data cannot be provided for NHS Trusts as they do not have a defined patient population.

Inpatient data (comorbidities)

This data presents a count of the number of comorbid conditions (and costs) when a patient is admitted to hospital. As with the admissions data comorbid conditions are counted during the first episode of an admission. Comorbid conditions are presented as four character ICD10 codes. The data is extracted in two ways:

- all secondary comorbidities when the neurological condition (e.g. MS) is a primary diagnosis
- as primary comorbidities when the neurological condition is a secondary diagnosis

References

Abraham S, Scheinberg LC, Smith CR, LaRocca NG (1997) **Neurologic impairment and disability status in outpatients with multiple sclerosis reporting dysphagia symptomatology**, J Neuro Rehab, 11:7–13.

Capita (2014) **The quality of clinical coding in the NHS: Payment by Results data assurance framework.** CHKS (part of Capita), Warwickshire UK.

Department of Health (2014) NHS Reference costs [27/11/14, updated 9/5/15]. Available at: www.gov.uk/government/publications/nhs-reference-costs-2013-to-2014 (Accessed 5 October 2015).

Department of Health (2015) NHS Reference cost guidance collection for 2014 to 2015. Available at: www.gov.uk/government/publications/nhs-reference-costs-collection-guidance-for-2014-to-2015 (Accessed 16 October 2015).

Dickens AM, Larkin JR, Griffin JL, Cavey A, Matthews L, Turner MR, Wilcock GK, Davis BG, Claridge TDW, Palace J, Anthony DC & Sibson NR (2014) **A type 2 biomarker separates relapsing-remitting from secondary progressive multiple sclerosis**, Neurology, 83:1492–1499.

Fowler CJ, Panicker JN, Drake M, Harris C, Harrison SCW, Kirby M, Lucas M, Macleod N, Mangnall J, North A, Porter B, Reid S, Russel N, Watkiss K & Wells M (2009) **A UK consensus on the management of the bladder in multiple sclerosis**, Postgrad Med J, 85:552–9.

Foxman B (2002) **Epidemiology of urinary tract infections: incidence, morbidity, and economic costs**, Am J Med, 113 Suppl:5S–13S.

Franklin GM & Nelson L (2003) **Environmental risk factors in multiple sclerosis: causes, triggers, and patient autonomy**, Neurology, 61:1032–4.

Harding KE, Wardle M, Moore P, Tomassini V, Pickersgill T, Ben-Shlomo Y & Robertson NP (2015) **Modelling the natural history of primary progressive multiple sclerosis**, J Neurol Neurosurg Psychiatry, 86:13–9.

Hirst C, Swingler R, Compston DAS, Ben-Shlomo Y & Robertson NP (2008) **Survival and cause of death in MS: A prospective population based study**, J Neurol Neurosurg Psychiatry, 79:1016-1021.

Jick SS, Li L, Falcone GJ, Vassilev ZP, Wallander MA (2015) **Epidemiology of multiple sclerosis: results from a large observational study in the UK**, Journal of Neurology, 262(9):2033-41.

Kalincik T, Buzzard K, Jokubaitis V, Trojano M, Duquette P, Izquierdo G, Girard M, Lugaresi A, Grammond P, Grand'Maison F, Oreja-Guevara C, et al. (2014) **Risk of relapse phenotype recurrence in multiple sclerosis**, Mult Scler, October 20(11):1511–22.

Lublin FD, Reingold SC, Cohen JA, Cutter GR, Sorensen PS, Thompson AJ, et al. (2014) **Defining the clinical course of multiple sclerosis: the 2013 revisions**, Neurology, 83(3):278-86.

Mackenzie IS, Morant SV, Bloomfield GA, MacDonald TM & O'Riordan J (2014) **Incidence and prevalence of multiple sclerosis in the UK 1990-2010: a descriptive study in the General Practice Research Database**, J Neurol Neurosurg Psychiatry, 85:76–84.

McDonald WI, Compston A, Edan G, Goodkin D, Hartung, H-P, Lublin FD, McFarland HF, Paty DW, Polman CH, Reingold SC, Sandberg-Wollheim M, Sibley W, Thompson A, Van Den Noort S, Weinshenker MD & Wilinsky MD (2001) **Recommended diagnostic criteria for multiple sclerosis: Guidelines from the international panel on the diagnosis of multiple sclerosis**, Ann Neurol, 50(1):121–127.

Miller DH, Weinshenker BG, Filippi M, Banwell BL, Cohen JA, Freedman MS, Galetta SL, Hutchinson M, Johnson RT, Kappos L, Kira J, Lublin FD, McFarland HF, Montalban X, Panitch H, Richert JR, Reingold SC & Polman CH (2008) **Differential diagnosis of suspected multiple sclerosis: a consensus approach**, Mult Scler, 14:1157–74.

MS Society (2014) MS in the UK. Available at: www.mssociety.org.uk/sites/default/files/MS in the UK.pdf (Accessed 16 October 2015).

Mutluay FK, Gürses HN, Saip S (2005) **Effects of multiple sclerosis on respiratory functions**, Clin Rehabil, 19(4):426-32.

Mynors G & Bowen A (2014) **MS specialist nursing in the UK 2014: The case for equitable provision**. Available at: www.mstrust.org.uk/downloads/case-for-equitable-provision-v7hr.pdf (Accessed 16 October 2015).

Mynors G, Suppiah J & Bowen A (2015) **Evidence for MS Specialist Services: Findings from the MS Trust GEMSS MS specialist nurse evaluation project**. Available at: www.mstrust.org.uk/gemss (Accessed 16 October 2015).

National Institute for Health and Clinical Excellence (2012) **Urinary incontinence in neurological disease: managment of lower urinary tract dysfunction in neurological disease.** NICE; London UK.

National Institute for Health and Clinical Excellence (2014) **Management of multiple sclerosis in primary and secondary care (Clinical Guideline 186)**. NICE, London UK.

Prosiegel M, Schelling A & Wagner-Sonntag A (2004) **Dysphagia and multiple sclerosis**, The International MS Journal, 11:22–31.

Rakusa M, Murphy O, McIntyre L, Porter B, Panicker J, Fowler C, Scott G & Chataway J (2013) **Testing for urinary tract colonization before high-dose corticosteroid treatment in acute multiple sclerosis relapses: prospective algorithm validation**, Eur J Neurol, 20:448–52.

Smeltzer SC, Utell MJ, Rudick RA & Herndon RM (1988) **Pulmonary function and dysfunction in multiple sclerosis**, Arch Neurol, 45(11):1245-9.

World Health Organization (2008) Atlas: **Multiple Sclerosis Resources in the World 2008**. Available at: www.who.int/mental_health/neurology/atlas_multiple_sclerosis_resources_2008/en/ (Accessed 16 October 2015).

Zajicek JP, Ingram WM, Vickery J, Creanor S, Wright DE & Hobart JC (2010) **Patient-orientated longitudinal study of multiple sclerosis in south west England (The South West Impact of Multiple Sclerosis Project, SWIMS) 1: protocol and baseline characteristics of cohort**, BMC Neurology, 10:88.

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