Re-audit on Unplanned Hospital Admissions in Patients with Neuromuscular Diseases

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Fighting muscle-wasting conditions

MRC Centre for Neuromuscular Diseases

NHS

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Highlights

More patients with neuromuscular conditions were under specialised care:

- 35.5% of admissions were related to patients known to a specialised neuromuscular service prior to hospital admittance as opposed to 16.2% in 2012
- The majority of admissions were under the care of Neurosciences (77%) as compared to 2012 when only 14.9% of admissions were admitted under neuroscience
- More patients were seen by a neurologist specialist (81.7%) during hospital admissions as compared with the 2012 audit (33.5%)

As a result some improvements were identified:

- The number of preventable admissions reduced from 37.5% in 2012 to 21.9% in 2017
- The proportion of preventable admissions directly related to a known neuromuscular condition reduced from 63% in 2012 to 32.8% in 2017
- Hospital stays were shorter among admissions related to patients known to a specialised service (median: 8 days) as opposed to patients who were not known to a specialised service where hospital admissions were longer (median: 15 days)
- Patients known to a specialised neuromuscular service had fewer ITU admissions (14.1%) than patients who were not known to specialised services (23.1%)
- The number of readmissions in people with neuromuscular diseases reduced from 25.1% in 2012 to 12.4% in 2017
- In hospital mortality frequency reduced from 4.5% in 2012 to 0.3% in 2017

Room for improvement:

- Emergency plan: Only five admissions had evidence of a clear and well-documented emergency plan prior to hospital admittance. Even excluding admissions where an emergency plan was not applicable, this number is very low
- Delayed discharges increased from 18.2% in 2012 to 25.2% in 2017

Introduction

Patients with neuromuscular diseases (NMDs) require long–term multi–disciplinary care. In England, this care should be co-ordinated by specialist neuromuscular services that are commissioned by NHS England. These centres provide diagnostic investigations, symptom management, treatment (when available) and multi-disciplinary care. Such centres also play an important role in the development of translational research. As a result, people with NMDs may experience an improvement in quality of life, prolonged life expectancy and receive advice on adaptations to help them carry out everyday tasks made harder by physical limitations. The knowledge and expertise generated at such specialised centres brings benefits worldwide through translational research dissemination.

Unplanned hospital admissions are more likely to happen if care is poorly co-ordinated and not proactive in preventing cardio-respiratory complications. In 2012, an audit to evaluate the proportion of unplanned hospital admissions occurring in people with NMDs was carried out across four NHS specialised commissioning groups: London, South Central, South East Coast and East of England regions.(1) The audit team reviewed 576 unplanned admissions for 395 patients with NMDs. Of those, only 16.2% (64/395) patients were known to a specialised service; and only seven of them had a documented emergency plan. Using a pre-planned audit tool it was concluded that 56.8% (327/576) of the admissions could not have been prevented. The measures thought to have the biggest impact that could have prevented the most admissions were: better patient surveillance, access to neuromuscular services and having an emergency care plan. (1) Key recommendations were developed. These included:

1. Monitoring of known neuromuscular patients and access to neuromuscular services between clinic appointments should be strengthened.
2. Specialist neuromuscular centres should coordinate care across different sub-specialities, avoiding fragmentation of care across different hospitals.
3. All patients with a known neuromuscular diagnosis should have a documented emergency plan.
4. Specialist neuromuscular centres should develop links with local hospitals to enable advice, diagnosis and referral to be managed in a timely fashion.
5. Specialist neuromuscular centres and commissioners should consider together whether other models of care or network arrangements would be an appropriate way to coordinate care for these patients.
6. Consideration should be given to undertaking further studies of unplanned or emergency admissions (outside of London and outside of specialist neuromuscular centres) to try and gain an understanding of the broader neuromuscular population.
7. All patients with a known neuromuscular condition should have a documented referral to a specialised neuromuscular team and an emergency plan on discharge. Health professionals should ensure that there is clear documentation of any review of a patient.

Aims

To re-audit unplanned hospital admissions directly related to NMDs and to compare the re-audit results with the previous audit report.(1) The impact of the previous audit on unplanned hospital admissions in this group of patients will be discussed.

Methods

A retrospective case note study of unplanned hospital admissions from 1st January 2014 to 30th June 2016 in patients with neuromuscular conditions was conducted. Twelve NHS Trusts who had previously participated in the 2012 audit were invited to take part. Trusts were visited by two neuromuscular clinical research associates across four specialised commissioning groups: London, Wessex, South East and East of England regions. Admissions were initially identified by NHS England - Specialised Commissioning using data from the Secondary Users Service (SUS) to identify admissions that were unplanned admission and that had a neuromuscular ICD-10 code in the primary or secondary diagnosis fields. Exclusion criteria were: incomplete medical notes, incorrect coding (elective/planned admissions), absence of a neuromuscular disease, admissions not directly related to a neuromuscular disease (eg.: appendicitis) and obstetric admissions. The test instrument (an encrypted laptop based electronic audit tool) was designed based on the previous audit report.(1) All data was anonymised and details of individual patients were omitted.

In this audit we used the same criteria for a potentially preventable admission described in the 2012 audit.

Note: For patients with multiple admissions within the audit time frame, demographic information was taken from the first admission (e.g.: age at first admission).

Results

In total, 361 consecutive unplanned hospital admissions were identified for 314 patients (age range: 0-94; median 55.5yrs), amounting to a total of 7,535 hospital bed days. Of these, 64 admissions required ITU care, amounting to 893 ITU bed days (median 9 ITU bed days). Of all admissions, 46 were paediatric admissions for 37 patients aged from 0 to 16ys (median 9yo), which amounted to a total of 759 hospital bed days (13 paediatric ITU admissions amounted to 136 paediatric ITU bed days; median 9 ITU bed days).

The length of stay ranged from zero to 231 days, with a median of 12 days. Length of stay for paediatric admissions ranged from zero to 114 days, with a median of 8 days. The duration of most admissions was longer than a week: only 123 admissions (34.1%) had a duration of one week or less.

Most admissions were followed A&E attendance (40.7%; 147/361). Most common admission routes among paediatric admissions were transfers from other hospital (17/46; 37%) and A&E attendance (16/46; 34.8%).

Discharge location was mostly to patients' homes (69.3%; 250/361). The same happened in the paediatric population (67.4%; 31/46).

The majority of patients were admitted only once during the re-audit time frame (275/314; 87.6%). 39 patients (12.4%) were admitted more than once; of these, eight were under the age of 16. Seven patients (2.2%) were readmitted three times or more. Such findings have improved compared with the 2012 audit where 99 patients (25.1%) had more than one admission.

When considering the paediatric population of this audit, seven patients were admitted twice and one child was admitted three times. This is a great improvement from 2012, when six paediatric patients had two admissions, four patients had three admissions, two patients had four admissions and one child had six admissions.

The majority of admissions were under the care of Neurosciences (77%; 278/361). This is an improvement compared with the 2012 audit when only 14.9% of admissions (86/576) were admitted under neuroscience. Patients were seen by a neurologist specialist in 295 admissions (81.7%; unknown: 20/361). This is an improvement compared with the 2012 audit when 33.5% of patients were seen by a neurology specialist. The proportion of patients being evaluated by a consultant also increased: from 88.1% to 93.2%.

In terms of specialised follow up, 263 admissions were linked to a specialist service, mostly neurology.

Neuromuscular Disease:
For 168 admissions (46.5%, unknown: 1 admission) the patients did not have a known NMD diagnosis prior to their hospital admission, while 192 admissions (53.2%) were related to a known NMD diagnosis or a suspected NMD under investigation (working diagnosis).

Neuromuscular junction disorders (101 patients; 121 admissions) and Guillain-Barre syndrome (98 patients, 103 admissions) were the most common NMDs associated with unplanned admissions. They amounted to 1,878 and 3,104 in hospital bed days respectively (24.9% and 41.2% of all bed days) and 268 and 439 ITU bed days respectively (30% and 49.2% of the ITU bed days).

Neuromuscular Service:
In 35.5% of the admissions the patients were known to a specialised service prior to hospital admittance (128/361) as opposed to 16.2% in 2012. Hospital stays were shorter among admissions related to these patients (median: 8 days) as opposed to patients who were not known to a specialised service where hospital admissions were longer (median: 15 days).

Patients known to a specialised neuromuscular service had fewer ITU admissions (18/128, 14.1%) than patients who were not known to such services (40/187, 23.1%).

Emergency Plan:
Only five admissions had evidence of a clear and well-documented emergency plan prior to hospital admittance. Even excluding admissions where an emergency plan was not applicable (e.g.: GBS), this number is very low.

ITU Admissions:
ITU admissions occurred in 64 (17.7%) of the 361 admissions; 10 admissions had incomplete data and it was unclear if there had or had not been ITU admission and thus cannot be commented on. Of those 64 ITU admissions, 13 were paediatric and 51 were related to people aged 17 or older. In 2012, there were 63 ITU admissions (10.9%), 20 of those cases were paediatric admissions. The proportion of ITU admissions increased

since 2012, but the proportion of preventable ITU admissions has reduced from 31.7% to 17.2% as addressed below (Preventability). The proportion of paediatric ITU admissions has also reduced: from 31.7% to 20.3%. The length of ITU admissions ranged from 1 to 102 days; (median: 9 days). Most of the ITU admissions were related to Guillain-Barre syndrome (27/64) and Myasthenia Gravis (25/64): 42.2% and 39.1% respectively. The longest ITU admission (102 days) was related to severe respiratory failure due to Myasthenia Gravis in a patient who was not previously diagnosed with a NMD.

Death:
One patient died during a hospital admission. Death resulted from medical complications (pulmonary embolism). This patient was admitted to an ITU with symptoms of Myasthenia Gravis. The patient was not previously diagnosed with an NMD and was not known to a specialised service prior to hospital admittance. The 'in hospital' mortality frequency represented 0.3% as opposed to 4.5% reported in 2012.

Preventability:
Admissions deemed to be preventable represented 21.9% of audit admissions. This is a great improvement compared to 37.5% of all preventable admissions reported in 2012. The improvement is more evident when analysing the proportion of preventable admissions directly related to a known neuromuscular condition, which reduced from 63% in 2012 to 32.8% in 2017. Preventable admissions (21.9%; n=79) amounted to 1,164 bed days. Possibly preventable admissions (19.4%; n=70) amounted to 1,079 bed days. When comparing to 2012 data, preventable admissions represented 37.5%, and possibly preventable 4.9% of all admissions.

The proportion of preventable admissions related to a known neuromuscular condition appears to have been reduced from 63%; (n=143/227) in 2012 to 32.8% (n=63/192) in this audit. The sum of both preventable and possibly preventable admissions in patients with a known neuromuscular condition was 68.7% (156/227) and 59.4% (114/192) in 2012 and in 2017 audit respectively.
Just over half of the admissions were considered to be not preventable (56.5%; 204/361); this compares with 29.5% (neuromuscular related admissions) in the 2012 audit. In 8 admissions (2.2%) preventability could not be determined. Eleven (17.2%) and 13 (20.3%) ITU admissions were preventable and possibly preventable respectively, amounting to 210 ITU bed days. This compares with 31.7% (preventable) and 9.5% (possibly preventable) ITU admissions in the 2012 audit

Measures that could have prevented unplanned admissions directly related to NMD included surveillance of patients' conditions, having an emergency plan and access to neuromuscular services.

Delayed Discharge:
In 91 sets of medical notes (25.2%) there was evidence of delayed discharge (unknown: 64/361). Medical complication (n=18), multiple factors (n=18), access to intermediate care (n=13), access to investigation/opinion (n=11) and access to other allied health care professionals (n=8) contributed most to delayed discharges. In 2012, 18.2% of the admissions were considered to have had a delayed discharge (105/576). The most common reason at the time was a delay in assessing investigation or a clinical opinion. Delayed discharges increased since 2012, but reasons for the delay have changed; most common reasons included medical complication, multiple factors and access to intermediate care.

Eight paediatric admissions (17.4%) had a delayed discharge (unknown: 10 admissions out of 46 paediatric admissions), which were associated with access to other allied health care professionals (n=3), accommodation / home equipment (n=2), investigation/opinion (n=1), delay in transfer to another hospital (n=1) and multiple factors (n=1). In 2012, five out of 41 paediatric admissions (12.2%) had a delayed discharge.

Conclusions

Unplanned hospital admissions are still an issue in patients with NMDs. We identified 421 unplanned admissions related to patients with NMD, but only 361 admissions were directly related to NMDs as opposed to the 2012 audit, which reported data on 576 neuromuscular hospital admissions.

Our re-audit demonstrated the following improvements for people with NMDs:

- More patients were known to a specialised service in the re-audit population;
- Most admissions were under the care of Neurosciences care as opposed to the previous audit (General Medicine). This may have contributed to the reduction in delayed discharge due to access to investigation/opinion;
- Most patients had a neurology review while in hospital by a Neurology Consultant;
- Patients known to a specialised neuromuscular service had a shorter hospital stay and fewer ITU admissions;
- The number of patients who had multiple admissions during the re-audit period was lower;
- The proportion of preventable admissions related to a known neuromuscular condition appears to have been reduced from 63%; (n=143/227) in 2012 to 32.8% (n=63/192) in this audit. The sum of both preventable and possibly preventable admissions in patients with a known neuromuscular condition was 68.7% (156/227) and 59.4% (114/192) in 2012 and in 2017 audit respectively;
- In this audit only one patient died compared with 26 deaths in the first audit;
- Delayed discharges have increased since 2012, but reasons for the delay have changed to include medical complication, multiple factors and access to intermediate care;
- A&E is still the most common admission route;
- The proportion of ITU admissions increased from 10.9% to 17.7%, but the proportion of paediatric ITU admissions has reduced from 31.7% to 20.3%;
- The proportion of preventable ITU admissions has reduced from 31.7% to 17.2%;

Key recommendations from previous audit improved the provision of NMD services, by containing the number of unplanned NMD hospital admissions over the past 5 years, reducing multiple admissions, enhancing the neurologist input in the management of acute admissions, shortening length of stay with fewer and shorter ITU admissions, reducing in hospital mortality rate and changing the reasons for delayed discharge.

However, emergency plans, one of the previous audit recommendations, were not recorded in the majority of the admissions. Further work is needed to make these part of the routine standard of care for an NMD patient.

Elective admissions at specialised neuromuscular services offer the opportunity to co-ordinate and organise proactive screening investigations for early treatment of NMD related complications (especially cardiac and respiratory), which can be combined with multi-disciplinary assessments. As a result, shorter elective admissions on a more regular basis could prevent future unplanned admissions which tend to be longer and often involve ITU.

Note: The following study limitations should be taken into account: data were not collected from three Trusts that had previously participated in the 2012 audit, medical notes unavailability and coding issues. Incomplete medical notes posed an extra challenge, highlighting the importance of having a standardised discharge form and guidance on its completion.

Recommendations

1. This audit suggests that there have been some improvements in the care of NMD patients since 2012, however, there is room for further improvement
2. Further work is needed to encourage centres to disseminate emergency care plans for all vulnerable patients

3. All patients should be referred to a specialist neuromuscular centre where their care can be co-ordinated
4. London and the South East coast is one of the only regions in the UK where patients do not have access to a care advisor. Care advisors in the community may help further to decrease unplanned admissions and reduce length of stay
5. NHS England Specialised commissioners, Clinical Commissioning Groups and Muscular Dystrophy UK should work in partnership through the new regional neuromuscular clinical networks ensure the full neuromuscular patient pathway is adequately supported across community, regional and national services
6. NHS England Clinical Reference Groups should include standards of care for patients with neuromuscular conditions as part of national paediatric neurology and neurology service specifications
7. All patients with a risk of being admitted to hospital in an emergency should be flagged with ambulance trusts across the South East of England

Next Steps

The findings of this re-audit will be presented to:

- The All-Party Parliamentary Group for Muscular Dystrophy
- The Pan-Specialised Commissioning Group Neuromuscular Working Group to take the recommendations forward
- The UK Neuromuscular Translational Research Conference

1 Introduction

Patients with neuromuscular diseases (NMDs) require long–term multi–disciplinary care. In England, this care may be provided by specialised neuromuscular Centres, which are usually commissioned by NHS England Specialised Services on a national and regional basis. Specialised NMD services provide diagnostic investigations, symptom management, treatment (when available) and multi-disciplinary care. Such centres also play an important role in translational research. As a result, people with NMDs may experience an improvement in quality of life, prolonged life expectancy and receive advice on adaptations to help them carry out everyday tasks made harder by physical limitations. The knowledge and expertise generated at such specialised centres brings benefits worldwide through translational research dissemination.

Patients with chronic NMDs frequently have multi-system involvement, which may require close follow-up and monitoring, multi-disciplinary care and social support. Unfortunately, unplanned hospital admissions in this group of patients are relatively common and may be a consequence of falls, cachexia, chest infections or cardiac problems. Access to specialised NMD services is still variable across the UK. It is thought that over 70,000 people in the UK have an NMD, which means unplanned hospital admissions in this population pose an additional cost to the NHS.(2) Such costs have been estimated to be high in London, the East of England, the South East Coast and the South Central regions.(3)

In 2012, an audit was performed to evaluate the proportion of unplanned hospital admissions related to NMD across four specialised commissioning groups: London, South Central, South East Coast and East of England regions.(1) The audit identified 576 unplanned admissions for 395 patients with NMDs. Of those, only 16.2% (64/395) patients were known to a specialised service; and only seven had a documented emergency plan. 56.8% (327/576) of the admissions could not be prevented. The measures thought to have the biggest impact that could have prevented the most admissions were better patient surveillance, access to neuromuscular services and having an emergency plan. Key recommendations were developed for the national working specification after consultation with the All Party Parliamentary Group for Muscular Dystrophy to reduce fragmentation of care.(1) These included

1. Monitoring of known neuromuscular patients and access to neuromuscular services between clinic appointments should be strengthened.
2. The specialist neuromuscular centre should coordinate care across different sub-specialities, avoiding fragmentation of care across different hospitals.
3. All patients with a known neuromuscular diagnosis should have a documented emergency plan.
4. Specialist neuromuscular centres should develop links with local hospitals to enable advice, diagnosis and referral to be managed in a timely fashion.
5. Specialist neuromuscular centres and commissioners should consider together whether other models of care or network arrangements would be an appropriate way to coordinate care for these patients.
6. Consideration should be given to undertaking further study of unplanned or emergency admissions (outside of London and outside of specialist neuromuscular centres) to try and gain an understanding of the broader neuromuscular population.
7. All patients with a known neuromuscular condition should have a documented referral to the neurology team and an emergency plan on discharge. Health professionals should ensure that there is clear documentation of any review of a patient.

To further address those issues, the following measures were taken:

- The audit results were disseminated at scientific and clinical education events
- The UK's first dedicated inpatient centre

for people with complex neuromuscular disorders was created at UCLH – Neuromuscular Complex Care Centre (NMCCC)

In 2013 Muscular Dystrophy UK launched a three year partnership approach project to improve healthcare and outcomes for people living with neuromuscular conditions in England. Some of the outcomes of the project include:

- The launch of the London and South East Coast Neuromuscular Clinical Network has been set up and is leading work to increase care coordination and support community health professionals across region
- 16 neuromuscular condition specific alert cards and a care plan to be used to inform health professionals in an emergency and coordinate care
- An online map of all neuromuscular clinics and specialist services in the UK to make it easier for patients and clinicians to access their local service
- The launch of the first ambulance flagging system for people with neuromuscular conditions living in London
- The upskilling of over 1700 physios and GPs in the care of people with neuromuscular conditions though online training modules
- Upskilling events for non-specialist health professionals working in the community
- £3.62 million of new NHS investment in the work force supporting people neuromuscular conditions in England

1.1 Aims

This audit of unplanned admissions focussed on the same criteria as the 2012 audit with the aim of identifying any positive changes in outcomes.(1) The impact of the 2012 audit on unplanned hospital admissions in this group of patients will be discussed.

2 Methods

A retrospective case note study of unplanned hospital admissions from 1st January 2014 to 30th June 2016 in patients with neuromuscular conditions was conducted. All NHS Trusts who participated in the 2012 audit were contacted and invited to take part in this audit.(1) Three Trusts who participated in the first audit chose not to participate on this occasion.

This collaborative audit was undertaken across the same four specialised commissioning groups (Table 1): London, Wessex, South East and East of England regions. The project was registered and approved by all Trusts' internal review board and audit committees. Honorary contracts were issued by all Trusts prior to data collection to enable review of medical notes were issued. As this was an audit project, informed consent was not required. All data was anonymised; details that could potentially identify patients' identity were omitted.

Nine out of 12 contacted Trusts were visited by two neuromuscular clinical research associates. Medical notes were reviewed during a 9-month-period from 1st September 2016 to 19th May 2017. A list of individual unplanned / emergency admissions was provided by NHS England. Admissions were initially identified by NHS England based on 1) specific admission method codes as per the NHS Data Model and Dictionary Version 3 (Appendix 1) and 2) neuromuscular ICD-10 code in the primary or secondary diagnosis fields (Appendix 2). The same ICD-10 code list was used in both the 2012 audit and this current re-audit. Exclusion criteria were: incomplete medical notes, incorrect coding (elective/planned admissions), absence of a neuromuscular disease, admissions not directly related to a neuromuscular disease (eg.: appendicitis) and obstetric admissions.

The test instrument (an encrypted laptop based electronic audit tool) was designed based on the previous audit report published in 2012.(1) It was piloted and validated by a neuromuscular clinical research associate using three sets of medical notes of NMD patients seen at the National Hospital for Neurology and Neurosurgery (UCLH). Data related to demographic details, underlying neuromuscular diseases, previous reviews at services specialised in NMDs, detailed information on unplanned hospital admissions, previous visits to A&E and documented emergency plans were collected. For patients with multiple admissions within the audit time frame, demographic information was taken from the first admission (e.g.: age at first admission). Data on preventability of admissions were collected and discussed with the audit clinical leader and/or neuromuscular consultants responsible for patients' admissions (when available). Consensus criteria for a potentially preventable admission were used based on the previous audit (Appendix 3). The previous audit's impact on unplanned admissions in this patients' population was discussed.

Table 1 – Number of admissions analysed in this re-audit by NHS Trust and site compared to the previous audit

Trust Name	NHS (Preliminary)	Excluded Cases					Total (n)**	2012 Audit
		UA notes	Incomplete data	Not NMD	Admission not directly related to NMD	Elective Admission	Admissions (Patients)	Admissions
Barts Health NHS Trust (Royal London and Whipps Cross)	135****	0	8	3	8	66	50 (40)	50
Brighton and Sussex University Hospitals NHS Trust	85***	31	6	2	2	10	34 (31)	66
Barking, Havering and Redbridge University Hospitals NHS Trust	20	X	X	X	X	X	X	32
The North West London Hospitals NHS Trust	7	X	X	X	X	X	X	58
Guy's and St Thomas' NHS Foundation Trust* (Evelina Children's)	0	-	-	-	-	-	0 (0)	6
Great Ormond Street Hospital for Children NHS Foundation Trust*	13	0	1	2	1	0	9 (7)	7
Homerton University Hospital NHS Foundation Trust	1	X	X	X	X	X	X	16
Imperial College Healthcare NHS Trust* (Charing Cross and Hammersmith)	63	34*	1	2	2	4	20 (20)	46
Oxford University Hospitals NHS Trust* (John Radcliffe)	119	-	7	7	20	12	73 (59)	103
University College London Hospitals NHS Foundation Trust*	51	0	0	4	10	12	25 (25)	37
Royal Free London NHS Foundation Trust*	61****	1	-	2	7	4	47 (36)	45
University Hospital Southampton NHS Foundation Trust*	146	9	2	10	10	12	103 (96)	110
Total (NHS Preliminary data)	701	-	-	-	-	-	-	UK
Total		75	25	32	60	120	361 (314)	576

NHS (Preliminary): number of records/admissions initially provided by NHS England; UA notes: no printed note was provided / available for review; Incomplete data: some or all data related to specific admissions were missing; not NMD: number of admissions where patients did not have neuromuscular diseases; UK: unknown; Grey rows: non-participatory Trusts; Right column ("2012 Audit"): previous audit results; * Denotes Trusts considered to have a specialist neuromuscular service; ** Number of admissions which met the inclusion / exclusion criteria and were reported in the results section; *** 86 admissions were initially provided, but one was recorded twice and so it was considered just one time; **** Hospital numbers which did not match the Trust records were excluded and were not mentioned in this report. ★Imperial Trust was able to provide medical notes close to the end of the re-audit time frame, which explains the high number of unavailable notes.

3 Results

We excluded admissions related to incorrect hospital numbers (eg.: some admissions contained the code “NULL” and for this reason we were unable to identify the correct patient to be reviewed) and one admission which was recorded twice. Of the remaining 701 admissions, 28 were excluded since they were related to three non-participatory Trusts as outlined in the re-audit methods section. 312 admissions did not meet inclusion/ exclusion criteria (unavailable medical notes: n=75; incomplete data: n=25, not a NMD disease: n=32; elective admissions: n=120; patients with an unplanned admission not directly related to an underlying NMD: n=60).

Consequently, we present in this report the results corresponding to 361 consecutive unplanned hospital admissions directly related to an underlying NMD for 314 patients (Figure 1).

Out of 314, 37 patients (11.8%) were under the age of 16; they and accounted for 46 admissions (12.7% of the total admissions).

39 patients (12.4%) were admitted on more than one occasion as illustrated in Table 2. Seven patients (2.2%) were readmitted three times or more. Of the 39 patients who were readmitted, eight were under the age of 16. The current data is presented compared with the previous audit report in Table 2 and shows a reduction in multiple admissions since 2012. Further discussion on data comparison is addressed in section 4.

Figure 1: Re-audit overview

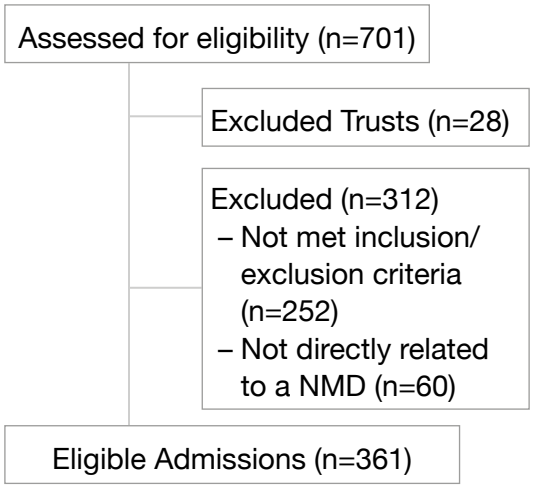


Table 2 – Number of admissions per patient according to underlying diagnosis			
Number of Admissions	Number of patients (%)	ICD-10*	2012 Audit Number of patients (%)
One	275 (87.6%)	(several)	296 (74.9%)
Two	32 (10.2%)	G70.0 Myasthenia gravis (n=11) G61.0 Guillan-Barre syndrome (n=6)** G61.8 Other inflammatory polyneuropathies (n=4) G62.8 Other specified polyneuropathies (n=2) G71.2 Congenital myopathies (n=2)** G71.3 Mitochondrial myopathy (n=2)** G12.0 Infantile spinal muscular atrophy (n=2)** G12.1 Other inherited spinal muscular atrophy (n=1)** G61.9 Inflammatory polyneuropathy, unspecified (n=1) G73.1 Eaton-Lambert syndrome (n=1)	55 (13.9%)
Three	6 (1.9)	G71.1 Myotonic disorders (n=1) G12.1 Other inherited spinal muscular atrophy (n=1)** G70.0 Myasthenia gravis (n=4)	26 (6.6%)
Four	1 (0.3%)	G61.8 Other inflammatory polyneuropathies (n=1)	11 (2.8%)
Five	0	-	2 (0.5%)
Six or more	0	-	5 (1.3%)
Total (patients)	314	-	395

* ICD-10 (as per Appendix 2).
** Seven children were admitted twice (ICD-10: G12.0 n=2; G71.2 n=2, G61.0 n=1; G71.3 n=1; G12.1 n=1) and one child was admitted three times (ICD-10: G12.1).

3.1 Patient Demographics

The audit population was 54.8% male (n=172) and 45.2% female (n=142). The audit population age ranged from 0 to 94 years, with a median age of 55.5 years. The age differences between the male and female cohorts are represented in Figure 2. Age ranged from 0 to 16 in paediatric patients, with a median age of 9 years.

For patients with multiple admissions, demographic information was taken from the first admission (age).

Figure 2: Male and female cohorts according to age range

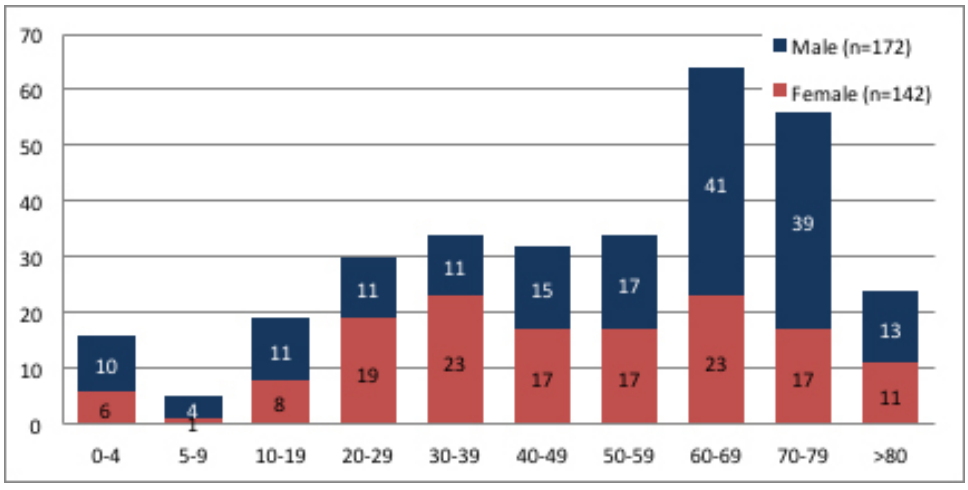


Figure 2 illustrated the number of patients according to age range and gender.

3.2 Neuromuscular Conditions

The most frequent neuromuscular condition associated with unplanned hospital admissions directly related to an underlying NMD in the analysed sample was a neuromuscular junction disorder, mostly characterised by Myasthenia Gravis (n=93). The most frequent NMD in the paediatric sample was Guillain-Barre syndrome, followed by Spinal muscular atrophy and related syndromes as shown in Table 3.

Table 3 - Neuromuscular conditions frequency in 314 patients with unplanned hospital admissions directly related to their underlying NMD

Neuromuscular Condition	All patients (re-audit sample n=314)	Paediatric patients* (n=37)
Myasthenia Gravis and other myoneural disorders and Myasthenic syndromes	101	3
Guillain-Barre Syndrome	98	10
Other inflammatory polyneuropathies; Unspecified inflammatory polyneuropathies (ICD-10: G61.8 and G61.9)	23	2
Other specified neuropathy	20	1
Inflammatory myopathies	20	2
Unspecified polyneuropathy	13	1
Spinal Muscular Atrophy and related syndromes	8	8
Muscular Dystrophy	6	1
Congenital Myopathies	6	6
Myotonic disorders	5	-
Diabetic polyneuropathy	4	-
Other specified myopathies	3	-
Mitochondrial Myopathy	3	1
Paraneoplastic neuromyopathy and neuropathy	2	-
Metabolic myopathies	2	2
Unspecified myopathy	1	-
Total NMD diagnostic frequencies	315**	37

* Paediatric cases were also represented in total sample results (n=314) ** one adult patient had 2 different NMDs and for this reason the total number of the diagnostic frequencies was greater than the total re-audit sample

3.2.1 No Previously Known Neuromuscular Disease Diagnosis

In 168 admissions (46.5%), the patients did not have an NMD diagnosis prior to their hospital admission (unknown n=1); four of them had been previously seen by a NMD specialist but had not yet got a working diagnosis of a suspected NMD on admission. Suggested diagnoses based on ICD-10 coding provided at discharge in those 169 admissions (including the unknown case) are reported in Table 4. The four patients previously seen by an NMD specialist with no known NMD diagnosis prior to hospital admission received the following ICD-10 coding at discharge: M33.2 (Polymyositis), G72.8 (Other specified myopathies), G62.9 (Polyneuropathy, unspecified) and G61.8 (Other inflammatory polyneuropathies) – for ICD-10: appendix 2.

Table 4 – New NMD diagnosis on discharge

New NMD diagnosis on discharge of patients with no known NMD diagnosis prior to hospital admission	Admissions
Guillain-Barre syndrome	91
Myasthenia Gravis and other neuromuscular junction disorders	33
Inflammatory Myopathies	13
'Other' specified neuropathy	10
'Other' inflammatory polyneuropathies, unspecified inflammatory polyneuropathies	9
Unspecified polyneuropathy	5
Paraneoplastic myopathy and neuropathy	2
Other specified myopathies	2
Diabetic polyneuropathy	1
Spinal muscular atrophy and related syndromes	1
Myotonic disorders	1
Unspecified myopathy	1
Total	169

Possible NMD diagnosis at discharge of patients with no NMD diagnosis prior to admission – based on ICD-10 coding.
NMD: neuromuscular disease.

3.2.2 Known Neuromuscular Disease Diagnosis

For 192 admissions (53.2%), a NMD diagnosis was known or was under investigation prior to hospital admission (working diagnosis was of a suspected NMD). This information was collected based on the comparison between medical notes information and ICD-10 code used on admission/discharge. Of those, 124 admissions were related to patients known to a specialised neuromuscular service prior to admittance (unknown n=26).

3.2.3 Known and not known to a Specialised Neuromuscular Service

Patients were known to a neuromuscular specialised service prior to hospital admission in 128 admissions (35.5%).

Admissions relating to patients not previously seen at a specialised service accounted for 51.8% of all admissions (n=187/361). In 46 admissions, there was no clear information on previous visits to a specialist and/or specialised NMD service (12.7%).

The duration of hospital stay was shorter for admissions related to patients who had previously been seen at a specialised service (median = 8 days) than for patients who were not known to a neuromuscular service (median = 15 days). Further details on hospital stay (bed days) were represented on section 3.4 (Table 6).

3.2.4 Emergency Plan

Only five admissions had evidence of a clear and well-documented emergency plan. Of them, four were patients known to a specialised service. Such cases amounted to 26 bed days: G71.0 was discharged on the same day, E74.0 was admitted for 16 days, G71.3 was admitted for two days, G71.2 was admitted for three days, and G12.1 was admitted for five days. Three of these were paediatric admissions.

For most patients there was no documentation relating to emergency care plans.

3.3 Intensive Therapy Unit Admissions

The majority of admissions in this audit did not require intensive therapy unit (ITU) care (79.5%; n=287/361; unknown: n=10). Length of stay on ITU ranged from 1 to 102 days (median: 9 days). Medical notes and discharge reports were incomplete for 8 ITU admissions from five different Trusts; those 8 admissions had to be excluded from the 'ITU bed days counting' because the admission and/or discharge dates were unknown. One of these excluded patients was admitted for at least 45 days in ITU (ICD-10: G70.0). The number of ITU bed days (893 days) represented (at least) 11.9% of the total hospital bed days (893/7,535).

Most of the ITU admissions were for Guillain-Barre syndrome (GBS) and Myasthenia gravis (MG): 42.2% and 39.1% respectively (Table 5). GBS related admissions (n=103 admissions) amounted to a total of 3,104 hospital bed days (median 19 days); 27 of the GBS cases required ITU care (not known: n=4), amounting to a total of 439 ITU bed days (median 18; unknown ITU admission date and/or discharge date: N=6). This represented 49.2% of the ITU bed days (439/893). GBS admissions are considered to be not preventable.

Of those cases, 37/74 were admitted via A&E, 21/74 were transferred from other hospital, 9/74 were referred by GPs, 3/74 were referred from an outpatient clinic (other: n=3; not known / not recorded n=1)

MG and related disorders (n=121 admissions in 101 patients) amounted to a total of 1,878 hospital bed days (median 9); 25 of the MG cases required ITU care (not known: 1), amounting a total of 268 ITU bed days (median 6; unknown: 2). MG and related disorders ITU admissions amounted to 30% of the ITU bed days (268/893). The longest ITU admission (102 days) was related to a patient with severe respiratory failure due to MG. This patient did not have a NMD diagnosis prior to hospital admission and was admitted via A&E to ITU. It was not mentioned in this patient's notes if there had been any assessment at a specialised service prior to hospital admittance.

Of the 25 admissions requiring ITU care in patients with a diagnosis of MG, 8 were considered preventable and 10 were possibly preventable (could not be determined: n=2). Further details on preventability are seen in section 3.5.

Table 5 – Number of Unplanned ITU Admissions according to Neuromuscular Disease

	All ITU Admissions	Paediatric ITU Admissions
ICD-10	Number of Admissions	Number of Admissions
G12.0 Infantile spinal muscular atrophy	1	1
G12.1 Other inherited spinal muscular atrophy	3	3
G61.0 Guillan-Barre syndrome	27	3
G70.0 Myasthenia gravis	25	1
G71.0 Muscular dystrophy	1	1
G71.2 Congenital myopathies	4	4
G72.4 Inflammatory myopathy, not elsewhere classified	1	-
M33.2 Polymyositis	2	-
Total	64	13

ITU: Intensive Therapy Unit; All ITU Admissions: Adult + Paediatric cases; ICD-10 list: Appendix 2.

The majority of patients utilising ITU bed days were not previously known to a neuromuscular specialised service: 40 admissions (unknown: 6) amounted to 70.3% of the total ITU bed days (628/893; unknown ITU dates: 6). A significant proportion of these admissions were due to GBS (n=27) as reported above.

Of the 128 admissions relating patients known to a neuromuscular service, 14.1% required ITU care (n=18), amounting to 130 ITU bed days; 14.6% of all ITU bed days (130/893). The majority of those patients had a diagnosis of MG. Thus, patients known to a specialised neuromuscular service had fewer ITU admissions (18/128, 14.1%) than patients who were not known to NM services (40/187, 23.1%) (p= 0.048, 95% CI -0.31 to 17.69).

3.3.1 Intensive Therapy Unit admissions in Paediatric Cases

There were 13 ITU admissions (28.3% of paediatric admissions; unknown: n=2) related to 11 paediatric patients. Those admissions utilised 136 ITU bed days (median: 9 days). 1 paediatric ITU admission did not have the ITU discharge date and was thus excluded from 'ITU bed days counting'. One paediatric patient with ICD-10 G12.1 was admitted three times within the re-audit time frame; all of those admissions required ITU care, amounting to 72 ITU bed days, which represented 52.9% of paediatric ITU bed days.

ITU admissions were more frequent among paediatric patients than admissions related to people aged 17 or older: 28.3% (13/46) and 16.2% (51/315) respectively (p = 0.045; 95% CI 0.99 – 27.78).

Table 6 – Hospital admissions, ITU admissions and bed days according to previous evaluation at specialised neuromsucular services

	All Re-audit Sample				Paediatric Sample			
	Not Known to a NMD service	Known to a NMD service	No Data	Total*	Paed: Not Known NMD Service	Paed: Known to a NMD Service	Paed: No Data	Paed: Total
Total Admissions	187	128	46	361	24	17	5	46
Total ITU Admissions	40	18	6	64	8	3	2	13
Bed Days								
Hospital Admission – days (%)	4,866 (64.6)	1,770 (23.5)	899 (11.9)	7,535	511 (67.3)	170 (22.4)	78 (10.3)	759
Median – Hospital Admission (days)	15	8	10.5	12	12.5	4	6	8
ITU Admission – days (%)	628 (70.3)	130 (14.6)	135 (15.1)	893**	87 (64)	19 (14)	30 (22)	136***
Median – ITU Admissions (days)	15.5	6	2	9	10	9	15	9

Total Admissions and ITU Admissions (first rows) were represented by admission numbers. Bed days were represented by hospital bed days and percentages. NMD service: specialised service for neuromuscular diseases; No Data: admissions with no information regarding previous appointment at a specialised service; ITU: intensive therapy unit; Paed: Paediatric Admissions - these results are part of the "All Re-audit Sample". *Including Paediatric cases; ** Eight ITU admissions were excluded from the bed day counting as medical notes related to those admissions were incomplete and did not contain admission date and/or discharge date. *** One paediatric case was excluded from ITU bed counting as no ITU discharge date was provided.

3.4 Admission Characteristics

3.4.1 Admission Route

Admission routes were provided by the NHS SUS (coding). The routes were updated and corrected if needed according to medical notes review. Most admissions were via Accident & Emergency (A&E), followed by transfers from other hospitals. Other admission routes are illustrated on Table 7.

Most common admission routes among paediatric admissions were transfers from other hospitals (17/46; 37%) and A&E (16/46; 34.8%).

The percentage of A&E admissions has decreased since 2012, with most admissions being via other routes.

Table 7 – Admission Routes

	Number of Admissions N (%)	Paediatric Admissions N (%)	2012 Audit N (%)
A&E	147 (40.7%)	16 (34.8%)	343 (59.5%)
Transfer from Other Hospital	64 (17.7%)	17 (37%)	72 (12.5%)
Clinic	50 (13.9%)	7 (15.2%)	54 (9.4%)
Other	27 (7.5%)	4 (8.7%)	4 (0.7%)
GP	25 (6.9%)	0	85 (14.8%)
Not known or not recorded	24 (6.7%)	0	6 (1.10%)
Home	13 (3.6%)	2 (4.3%)	2 (0.3%)
Other Department/Specialty	11 (3%)	0	10 (1.7%)
Total	361*	46	576

Clinic: direct admissions from clinic. *Including paediatric admissions

3.4.2 Admitting Specialty

Most admissions were managed by Neurosciences as shown in Table 8. This has changed substantially since 2012.

Table 8 – Admitting Specialty

Service	Number of Admissions (%)	2012 Audit
Neurosciences	278 (77)	86 (14.9)
Neurology	276 (76.5)	
Stroke Unit	2 (0.5)	
Paediatrics	43 (11.9)	63 (10.9)
Paediatrics	32 (8.9)	
Paediatric Respiratory	5 (1.4)	
Paediatric Neurology	4 (1.1)	
Paediatric ITU	2 (0.5)	
Other Specialties	34 (9.4)	
General Medicine	12 (3.3)	306 (53.1)
Rheumatology	7 (1.9)	8 (1.4)
ITU	5 (1.4)	9 (1.6)
Respiratory medicine	2 (0.5)	5 (0.9)
Thoracic Medicine	2 (0.5)	
A&E	1 (0.3)	13 (2.2)
Gastroenterology	1 (0.3)	3 (0.5)
Medicine of Elderly	1 (0.3)	5 (0.9)
Haematology	1 (0.3)	2 (0.3)
Cardiology	1 (0.3)	6 (1.0)
Surgery	1 (0.3)	32 (5.5)
Unknown	6 (1.7)	5 (0.9)
Others	-	33
Total	361	576

3.4.3 Neurology Review

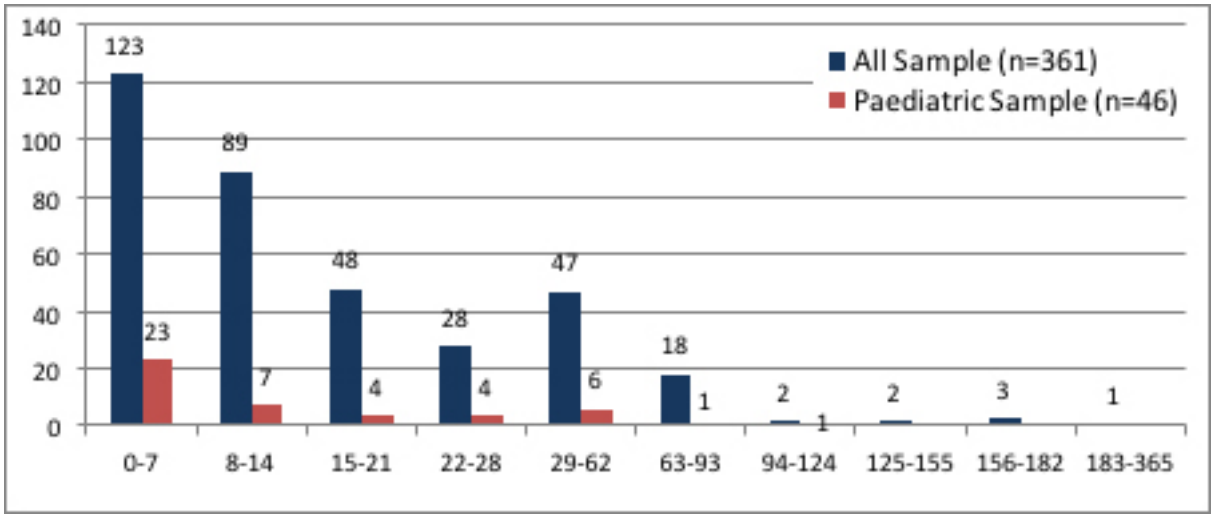
A neurology review took place in 81.7% (n=295/361) of admissions (not seen by a neurology specialist: 46; unknown: 20). This is much improved since the 2012 audit. This was carried out by a neurology consultant in 275 admissions (on at least one day of the patients' hospital admission). In 17 admissions patients were assessed by neurology SpR and in 3 admissions by a Clinical Nurse Specialist (Myasthenia Gravis).

3.4.4 Length of Stay

In this audit sample (n=361) hospital stay amounted to 7,535 hospital bed days (759 days for paediatric admissions). Length of stay ranged from zero to 231 days, with a median of 12 days. 34.1% of the admissions had a length of stay of one week or less (n=123): in 7 admissions, patients were discharged on the same day; in 13 admissions, patients were discharged the next day of admittance; 18 for 2 days; 8 for 3 days; 25 for 4 days; 15 for 5 days; 20 for 6 days; and 17 for 7 days.

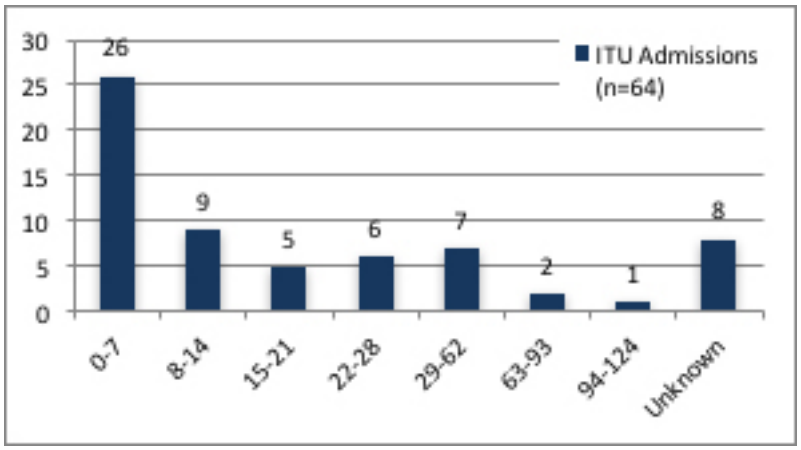
The length of stay for paediatric admissions ranged from zero to 114 hospital days (median: 8). Figure 3 illustrates length of stay according to number of hospital bed days in both re-audit patients (all sample) and paediatric sample (the 46 paediatric admissions were also represented in "All Sample" results). Figure 4 shows length of stay in ITU.

Figure 3 – Length of hospital stay (n=361)



Number of admissions according to hospital bed days (days range). Paediatric admissions were also represented in "All Sample" results.

Figure 4 Length of ITU stay (n=64)



Number of ITU admissions according to ITU hospital bed days – length of stay

3.4.5 Discharge Location

In the majority of admissions (n=250, 69.3%), patients were discharged to home.

As might be expected for the paediatric population, in most of the admissions patients were discharged to home (n=31; 67.4%). Further information on discharge locations are shown in Table 9.

Table 9 – Discharge Location

	Number of Discharges (%)	Paediatric Admissions	2012 Audit
Home	250 (69.3)	31	444 (77.1)
Unclear or not recorded	41 (11.3)	2	12 (2.1)
Intermediate care	31 (8.6)	1	12 (2.1)
Transfer back to referring hospital	14 (3.9)	4	19 (3.3)
Transferred to another hospital	11 (3)	2	49 (8.5)
Nursing care	10 (2.8)	4	9 (1.5)
Back to residential care	3 (0.8)	2	5 (0.9)
Not applicable as patient died	1 (0.3)	0	26 (4.5)
Total	361*	46	576

3.4.5.2 Delayed Discharge

Information on delayed discharges was not routinely collected, and was not available in 64 admissions (10 of those unknown cases were paediatric admissions). Reasons for delayed discharges were recorded for 91 admissions, which were summarised in Table 10. “Access to rehab/intermediate care” was usually related to unavailable beds.
Eight paediatric admissions had a documented delayed discharge, which were associated with access to other allied health care professionals (n=3), accommodation/ home equipment (n=2), investigation/opinion (n=1), delay in transfer to another hospital (n=1) and multiple factors (n=1).

3.4.6 Specialist Follow Up

263 patients were linked to a specialist (not linked: n=61; not clear/unknown: n=37).
The majority of admissions were linked to neurology only (n=150); 14 admissions were linked to neurology and other specialities, and 15 admissions were linked to paediatric neurology. In 84 admissions, patients were referred to other specialties (e.g.: rehabilitation). Patients who were previously known by a specialised service were generally referred back for a follow-up.

Table 10 – Reasons for Delayed Discharge

Reason for Delayed Discharge	Number of Admissions	2012 Audit
Medical complications*	18	13
Multiple factors**	18	-
Access to rehab / intermediate care	13	18
Access to investigations / specialist opinion	11	44
Access to other allied health care professionals	8	4
Delay in transfer to another hospital	5	10
Unclear from notes	5	
Accommodation / home equipment	3	11
Social care input / package of care	3	17
Access to physiotherapy / occupational therapy	2	3
Others	5	12
Total	91	132

*medical complications (e.g.: pulmonary embolism, hospital-acquired infection, etc)
** When more than 3 interventions contributed to delayed discharge (e.g.: awaited bed, awaited access to investigations and had medical complications)

3.5 Was the Admission Preventable?

Most of the admissions were considered to have been 'not preventable' as seen in Table 11 (56.5%; 204/361 – could not be determined: 2.2%; n=8). 'Not preventable' admissions included those with acute presentation, first manifestation of a chronic condition, required inpatient care and/or investigation. Examples of non-preventable admissions are those related to GBS, which accounted for 103 admissions as mentioned above (Section 3.4).

Preventable admissions (21.9%; n=79) amounted to 1,164 bed days. Possibly preventable admissions (19.4%; n=70) amounted to 1,079 bed days. Eleven (17.2%) and 13 (20.3%) ITU admissions (could not be determined: 3.1%; n=2/64) were preventable and possibly preventable respectively, amounting to 210 ITU bed days (86 and 124 days respectively as per table 11).

3.5.1 Neuromuscular Disease Diagnosis

Of the admissions related to patients who did not have a known diagnosis prior to admission (n=168; unknown: n=1), 122 were not preventable (72.2%). Of the four admissions related to patients previously seen by a specialised doctor who did not have a NMD diagnosis or a working diagnosis prior to hospital admission, two were not preventable; one (seen at a private clinic) was possibly preventable if an elective admission for diagnostic investigation had been booked at an earlier stage prior to disease progression (prevent diagnosis delay); in one admission, preventability could not be determined.

Of those admissions related to patients with a previously known NMD diagnosis (n=192), 63 were preventable (32.8%), 51 were possibly preventable (26.6%), 71 were not preventable (37%) and seven could not be determined (3.6%). Preventable and possibly preventable admissions related to patients with a known neuromuscular condition accounted for 59.4% (114/192).

A comparison between the preventability data reported in 2012 and data presented here is shown in Table 13. Measures that could have prevented unplanned admissions directly related to NMD are shown in Table 15.

Table 11 – Preventability of Unplanned Admissions Direclty Related to NMDs						
	All Admissions		Paediatric Admissions		ITU Admissions	
	Admissions	Hospital bed days – Total (Median)	Paed Admissions	Hospital bed days – Total (Median)	ITU Admissions	ITU bed days (median)
No	204	5,084 (14)	23	450 (9)	38	683 (16)*
Yes	79	1,164 (7)	12	210 (15)	11	86 (6)
Possibly	70	1,079 (10)	9	96 (6)	13	124 (4)
Could not be determined	8	208 (9.5)	2	3 (1.5)	2	UK**
Total	361***	7,535***	46	759	64	893

* six admissions had no ITU admission and/or discharge dates, they were excluded from ITU bed days count; ** both admissions had incomplete data regarding ITU admission and/or discharge date; ***Including paediatric admissions; ITU: Intensive Therapy Unit; Paed: Paediatric admissions. UK: unknown

Table 12 – Preventability of admissions according to a previously known neuromuscular disease and previously review at a specialised neuromuscular service							
	No known NMD diagnosis prior to admission			Known NMD prior to admission			All Admissions
Preventability	Not at specialised service	Seen by specialised service	Unknown status	Not at specialised service	Seen by specialised service	Unknown status*	
No*	122	2	9	22	40	9	204
Yes	9	0	7	8	46	9	79
Possibly	14	1	4	11	34	6	70
Could not be determined	0	1	0	1	4	2	8
Total Admissions	169			192			361

* No: could not be preventable; eg.: acute presentation (e.g.: Guillain-Barre syndrome), first manifestation of a chronic condition, required inpatient care and/or investigation; NMD: Neuromuscular Diseases; Unknown status: it was not possible to determine if the patient was known to a NMD service; ** neuromuscular related admissions

Table 13 Preventability in 2012 and in 2017 audits								
	All Admissions 2017	All Admissions 2012	NMD Admissions 2017	NMD Admissions 2012	Paediatric Admissions 2017	Paediatric Admissions 2012	ITU Admissions 2017	ITU Admissions 2012
No	204 (56.5%)	327 (56.8%)	71 (37%)	67 (29.5%)	23 (50%)	39 (59.1%)	38 (59.4%)	34 (54%)
Yes	79 (21.9%)	216 (37.5%)	63 (32.8%)	143 (63%)	12 (26.1%)	19 (28.8%)	11 (17.2%)	20 (31.7%)
Possibly	70 (19.4%)	28 (4.9%)	51 (26.6%)	13 (5.7%)	9 (19.6%)	5 (7.6%)	13 (20.3%)	6 (9.5%)
Could not be determined	8 (2.2%)	5 (0.9%)	7 (3.6%)	4 (1.8%)	2 (4.3%)	3 (4.5%)	2 (3.1%)	3 (4.8%)
Total Admissions	361	576	192	227	46	66	64	63

NMD: known neuromuscular disease

Table 14 – Delayed discharge by preventable and non-preventable admissions		
	Delayed discharge (admissions)	2012 Audit
Preventable	16	52
Possibly preventable	10	6
Non-preventable	62	47
Could not be determined	3	-
Total	91	105*

* based on Table 13 from the 2012 audit report (1)

The majority of interventions and/or measures that could have prevented or possibly prevented the 149 admissions shown in Table 11 and 12 were related to surveillance of patients' condition (Table 15). As reported before, a clear emergency plan was not documented in the majority of hospital notes; emergency plans could have/possibly have prevented 44 admissions (33 in association with lack of condition surveillance). Early referral to a specialist (neurology or neuromuscular) and prevention of diagnosis delay would also have contributed to reducing those numbers.

Elective admissions at a specialised service with experience in neuromuscular disease could contribute to a short stay admission for diagnostic investigation, treatment adjustment / administration, investigation of a known NMD complication, condition surveillance, and/or liaison with other services (i.g.: psychology, physiotherapy). As more than one intervention/measure could fit under "Elective admission" intervention, we considered on Table 15 only the 13 cases where admissions were most probably not urgent – but were recorded with NHS unplanned / emergency admission codes.

Table 15 – Measures which could prevent or poissibly prevented unplanned or emergency admissions directly related to a NMD

Intervention / measure	Admissions	2012 Audit
Surveillance of patients' condition		
Surveillance of patient's condition **and** Having an emergency plan	33	
Surveillance of patient's condition	15	114
Having an Emergency Plan	11	59
Early readmission with an existing avoidable problem related to NMD	4	
Access to Services		
Access to neuromuscular services	16	98
Prevent delay in referral to a neurology service	13	11
Prevent diagnosis delay	9	8
Patient/parent education **and** Access/liaison to other services	3	18 and 13
Related to Hospital Admission		
Monitoring repeated admissions for recurrent symptoms	10	4
Having a discharge plan	4	4
Having an elective admission at a specialised service	13	
Others		
Multiple factors	8	
Other	5	18
Provision of equipment	3	34
Other condition management (DM)	2	
Total	149	381

DM: diabetes mellitus

4 Discussion

We have reviewed documents and medical notes related to 598 admissions. Of them, 421 unplanned admissions were related to patients with NMD, 361 of these admissions met re-audit inclusion criteria; they represented unplanned hospital admissions directly related to NMDs in 314 patients from 1st January 2014 to 30th June 2016 from 9 Trusts across four specialised commissioning groups: London, Wessex, South East and East of England regions.

4.1 Re-audit Limitations and Challenges

Trusts: Limitations were related to receiving a positive reply from all Trusts (three Trusts declined), organising honorary contracts for both clinical fellows, registering the audit project under the local audit committee and having medical notes available for review.

One Trust (Imperial) was only able to provide medical notes at the end of the audit project, which explains the high number of unavailable notes seen in Table 1.

Medical Notes: Data collection was hampered in Trusts where printed medical notes were the only source of medical information. Factors that contributed to the unavailability of notes included archiving issues, admitted patients (notes where located on hospital wards), deceased patients, research and clinic purposes (notes were temporarily stored by different departments). Another limitation of printed medical notes was that, at times, handwriting was illegible.

Incomplete medical information recorded in patients' notes was an important limitation for data collection. Unfortunately, incomplete (or absent) discharge summaries were a common problem, for example eight ITU admissions had missing ITU admission/discharge dates, which compromised analysis of ITU length of stay and ITU bed days. When discharge summaries were available, their content varied greatly. Some of the long admissions also lacked further details on the reason for delayed discharge.

Coding: We received a list of records from NHS England containing unplanned / emergency admissions. Surprisingly, discharge summaries for some of these indicated that they were an "elective admission", which may illustrate a coding issue. We excluded 120 elective admissions that were preliminarily "filtered" as unplanned/ emergency. It is possible that a few elective admissions were still included in the re-audit sample (n=361); the lack of clear information restricted us to exclude such cases from data analysis as they also had an emergency NHS code. In this scenario, we are aware that this could potentially interfere with preventability analysis, as it is unsure how many of the preventable admissions were actually a wrongly coded elective admission. We have highlighted in Table 15 thirteen preventable admissions that were most probably not urgent as an elective admission could have provided the required care.

Coding limitations illustrate the importance of recording specific information on the discharge summary.

We selected cases where the ICD-10 code was recorded as a primary or secondary diagnosis field to be consistent with the previous audit project. As explained in the previous report, it is possible that some cases were missed due to neuromuscular diagnosis being in a lower order diagnostic field.(1) Thirty-two admissions were excluded because the patients actually did not have a neuromuscular disease, which could also illustrate other aspects of coding issues. Note: New Admission Method codes 2A, 2B, 2C and 2D were introduced from 2013-2014 to replace the single code 28 "Emergency Admission Other Means". This old national code will be retired in the next version of the Commissioning Data Set but may still be used by providers. For this reason, we most probably have used different NHS codes

than the previous audit; this will be difficult to confirm, as a list containing the codes used in 2012 was not provided in the first audit report. However, it is not entirely clear if such changes have made a substantial difference between both audits preliminary admissions "screening"/filtering.

Preventability: As reported above, wrong coding could also have overestimated preventability rates as elective admissions could have been coded as unplanned / emergency admissions.

Whenever needed, preventability selection criteria were also discussed with responsible consultants at different Trusts (when available).

Inclusion / Exclusion Criteria: We provided clear inclusion and exclusion criteria, NHS coding list and ICD-10 list to facilitate future re-audit reproduction. We also described the amount of expected admissions to be reviewed (preliminary NHS list: n=701) and the number of excluded cases (Table 1, Figure 1). We only analysed admissions directly related to an underlying NMD (e.g.: admissions to treat appendicitis were excluded).

Although the same ICD-10 coding list was used as the original 2012 audit, the NHS coding system was changed between both audits as mentioned above. This might possibly have led to some imprecision in the comparison of data between the two audits.

4.2 Most Important Results and Comparison with the Previous Audit Report

Unplanned hospital admissions are still an important issue in patients with NMDs. We have identified 421 unplanned admissions in patients with NMD; in 361 of them, the admission was directly related to the underlying NMD. Such findings opposed the 2012 audit results, which reported data on 576 hospital admissions;

Given the limitations described above this audit indicates that some positive changes have taken place for patients since 2012.

Patient Demographics
Similar patient demographics were found in both audits with regards to gender and age, illustrating that NMDs are prevalent in all age range and genders.

The number of readmissions in people with neuromuscular diseases reduced from 25.1% in 2012 to 12.4% in 2017.

In this audit, the majority of patients had only one admission within this audit's time frame (87.6%), which was improved compared with 2012 (74.9%). Only 10.2% and 1.9% of the re-audit patients had two or three admissions respectively, compared with the 2012 audit where 13.9% and 6.6% of patients were readmitted twice and three times respectively. In 2012 4.6% of patients had four or more admissions; however, in this re-audit study, none of the patients had more than three admissions.

When considering the paediatric population of this audit, seven patients were admitted twice and one child was admitted three times. This is a great improvement from 2012, when six paediatric patients had two admissions, four patients had three admissions, two patients had four admissions and one child had six admissions.

Neuromuscular Diseases and Neuromuscular Services
The most frequent neuromuscular conditions associated with unplanned hospital admissions were neuromuscular junction disorders and Guillain-Barre syndrome (GBS), which was similar to the 2012 audit. In the re-audit paediatric sample, GBS and Spinal muscular atrophy and related syndromes accounted for the most common diagnoses. The previous audit report identified a high frequency of neuropathies, which included alcohol related neuropathy (n=13) and diabetic polyneuropathy (n=31).

Almost half of the admissions (46.5%) related to patients who did not have a previously known diagnosis; the majority of these were due to acute presentations of GBS in previously healthy people, which explain

the lack of diagnosis at admission and the unavailability of an emergency plan. These admissions were not preventable because GBS is an acute condition.

There were, however, patients with symptoms of chronic NMDs and no previous diagnoses. Such patients received a new diagnosis at discharge, to include Myasthenia Gravis. These patients highlight the importance of early referral to a neurology specialist and/or neuromuscular specialised service for diagnostic investigations in order to improve symptom management, quality of life, reduction in emergency admissions and improvement in delayed discharges.

35.5% of admissions were related to patients known to a specialised neuromuscular service prior to hospital admittance as opposed to 16.2% in 2012.

In this audit we found that a greater proportion of patients were known to a specialised service than in 2012. This indicates a positive impact from the previous audit recommendations on improving the access to specialised neuromuscular services.

This audit has also found that those patients known to a specialised neuromuscular service required a shorter hospital stay and fewer ITU admissions, which also highlighting the benefit of patients attending specialist NMD centres.

Emergency Plan

In this audit only five admissions had a clear and well-documented emergency plan. However, it was not clear as to whether these were not provided by the NMD service or whether patients did not carry them to hospital or whether they were simply not documented.

However, in those admissions where there was a documented emergency care plan the length of stay tended to be shorter (0, 2, 3 and 5 days) with the exception of one patient (16 bed days) who was admitted for diagnostic investigation and symptom management. In addition, this audit identified that the availability of an emergency plan might have prevented 44 admissions (33 in association with condition surveillance). Thus, further work in developing these plans for all NMD patients is highly recommended

Intensive Therapy Unit

ITU admissions were not common, but most of the ITU bed days were related to patients who were not previously known to a specialised neuromuscular service (70.3%). Similar findings were seen among the paediatric ITU admissions (64% Paediatric ITU bed days). Most of the ITU admissions were related to GBS and to Myasthenia Gravis. Patients known to a specialised neuromuscular service had fewer ITU admissions.

Eight sets of medical notes / discharge summaries did not record ITU admission/ discharge dates thus this data could not be recorded.

11 paediatric patients had an ITU admission, amounting to 13 ITU admissions as compared to 20 admissions reported in 2012. One patient (G12.1 - Other inherited spinal muscular atrophy) had three ITU admissions, which amounted to 52.9% of all paediatric ITU bed days (72/136).

Admission Characteristics

Most of the admissions were either directly via A&E (40.7%) or transfers from other hospitals (17.7%). The previous audit reported A&E (59.5%) and GP (14.8%) as the main admission route. The availability of an emergency plan for GPs could improve local care and potentially reduce the number of A&E visits, as the initial treatment required might possibly be provided in the community. In the event of A&E visits, an emergency plan could also help the on-call doctor provide specific and “personalised” care, which could facilitate medical management and potentially reduce the re-admittance rate.

The majority of admissions were under the care of Neurosciences (77%) as compared to 2012 when only 14.9% of admissions were admitted under neuroscience.

The 2012 audit showed that most patients were admitted under General Medicine (53.1%) care and only 14.9% were to Neurosciences. This has greatly changed in this audit (3.3% to General Medicine and 77% to Neurosciences).

More patients were seen by a neurologist specialist (81.7%) during hospital admissions as compared with the 2012 audit (33.5%)

A great difference was also noted in neurology review reports: no documented Neurology review took place in the majority of the 2012 audit admissions (58.3%). In this audit only 12.7% patients were not seen by a neurologist (not known: n=20), suggesting significant improvement since 2012. A neurology consultant carried out a neurology review in 275 admissions. This is also an improvement compared with the 2012 audit when 170 patients were seen by a consultant. Both audits showed that most patients are discharged to home. For 11.3% of the admissions it was not possible to comment due to unclear or not recorded discharge locations in the records.

Delayed Discharge

Delayed discharges increased from 18.2% 2012 to 25.2%.

A delayed discharge was documented in 91 admissions (25.2%), which was higher than the 2012 audit (18.2%). However, the reasons for delayed discharge have changed. In 2012, the most common cause was the delay in accessing investigations or a clinical opinion (41.9%), which counted for only 12.1% of the 2017 delayed discharges. The increased number of admission under Neurology care could have greatly contributed to this decrease by providing more appropriate specialised and multi-disciplinary care. Delayed discharge caused by problems with social care input / package of care (3.3%) was also less of a problem for this audit than 2012. This could be explained by better co-ordinated care by neuromuscular teams.

Preventability

The number of preventable admissions reduced from 37.5% in 2012 to 21.9% in 2017.

The proportion of preventable admissions directly related to a known neuromuscular condition reduced from 63% in 2012 to 32.8% in 2017.

Most of the admissions identified in this audit were not preventable (56.5%; 204/361). This was mostly due to a first presentation of a NMD that required in hospital investigation and treatment, or to an acute presentation of a NMD in a previously healthy person (e.g.: GBS non-preventable admissions).

The proportion of preventable admissions related to a known neuromuscular condition identified in this audit was 32.8% (n=63/192), which is much lower than 63% reported in 2012. When considering both preventable and possibly preventable admissions in patients with a known neuromuscular condition, results from both audits were similar: 68.7% (156/227) in 2012 and 59.4% (114/192) in this re-audit.

Measures that could have prevented unplanned admissions include: the presence of a documented emergency care plan, co-ordination of care via a specialist neuromuscular service, early referral to Neurology during acute admission and the use of care advisors in the community.

Death

In hospital mortality frequency reduced from 4.5% in 2012 to 0.3% in 2017.

One patient died during a hospital admission in this audit. The cause of death was pulmonary embolism, which emphasises the importance of preventing admissions in this group of patients. This was a marked improvement from the 2012 audit which reported 26 deaths.

Incomplete Notes

As mentioned in several sub-sections within the Results (section 3), not all patients had all information required to complete all the required fields within the re-audit tool. This highlights the need for better documentation of all hospital admissions.

Conclusions

Unplanned hospital admissions are still an issue in patients with NMDs. We identified 421 unplanned admissions related to patients with NMD, but only 361 admissions were directly related to NMDs as opposed to the 2012 audit, which reported data on 576 neuromuscular hospital admissions.
Our re-audit demonstrated the following improvements for people with NMDs:

- More patients were known to a specialised service in the re-audit population;
- Most admissions were under the care of Neuroscience care as opposed to the previous audit (General Medicine). This may have contributed to the reduction in delayed discharge due to access to investigation/opinion;
- Most patients had a neurology review while in hospital by a Neurology Consultant;
- Patients known to a specialised neuromuscular service had a shorter hospital stay and fewer ITU admissions;
- The number of patients who had multiple admissions during the re-audit period was lower;
- The proportion of preventable admissions related to a known neuromuscular condition appears to have been reduced from 63%; (n=143/227) in 2012 to 32.8% (n=63/192) in this audit. The sum of both preventable and possibly preventable admissions in patients with a known neuromuscular condition was 68.7% (156/227) and 59.4% (114/192) in 2012 and in 2017 audit respectively;
- In this audit only one patient died compared with 26 deaths in the first audit;
- Delayed discharges have increased since 2012, but reasons for the delay have changed;
- A&E is still the most common admission route;
- The proportion of ITU admissions increased from 10.9% to 17.7%, but the proportion of paediatric ITU admissions has reduced from 31.7% to 20.3%;

The proportion of preventable ITU admissions has reduced from 31.7% to 17.2%;Key recommendations from previous audit improved the provision of NMD services, by containing the number of unplanned NMD hospital admissions over the past 5 years, reducing multiple admissions, enhancing the neurologist input in the management of acute admissions, shortening length of stay with fewer and shorter ITU admissions, reducing in hospital mortality rate and changing the reasons for delayed discharge.

However, emergency plans, one of the previous audit recommendations, were not recorded in the majority of the admissions. Further work is needed to make these part of the routine standard of care for an NMD patient.

Elective admissions at specialised neuromuscular services offer the opportunity to co-ordinate and organise proactive screening investigations for early treatment of NMD related complications (especially cardiac and respiratory), which can be combined with multi-disciplinary assessments. As a result, shorter elective admissions on a more regular basis could prevent future unplanned admissions which tend to be longer and often involve ITU.

5 Re-audit Recommendations

1. This audit suggests that there have been some improvements in the care of NMD patients since 2012, however, there is room for further improvement
2. Further work is needed to encourage centres to disseminate emergency care plans for all vulnerable patients
3. All patients should be referred to a specialist neuromuscular centre where their care can be co-ordinated
4. London and the South East coast is one of the only regions in the UK where patients do not have access to a care advisor. Care advisors in the community may help further to decrease unplanned admissions and reduce length of stay
5. NHS England Specialised commissioners, Clinical Commissioning Groups and Muscular Dystrophy UK should work in partnership through the new regional neuromuscular clinical networks ensure the full neuromuscular patient pathway is adequately supported across community, regional and national services
6. NHS England Clinical Reference Groups should include standards of care for patients with neuromuscular conditions are included as part of national paediatric neurology and neurology service specifications
7. All patients with a high risk of being admitted to hospital in an emergency should be flagged with ambulance trusts across the South East of England

6 Next Steps

The findings of this re-audit will be presented to:

- The All-Party Parliamentary Group for Muscular Dystrophy
- The Pan-Specialised Commissioning Group Neuromuscular Working Group to take the recommendations forward
- The UK Neuromuscular Translational Research Conference

7 Appendices

7.1 Appendix 1: NHS coding list - National Codes

Emergency Admission, when admission is unpredictable and at short notice because of clinical need:

21 Accident and emergency or dental casualty department of the Health Care Provider

22 GENERAL PRACTITIONER: after a request for immediate admission has been made direct to a Hospital Provider, i.e. not through a Bed bureau, by a GENERAL PRACTITIONER or deputy

23 Bed bureau

24 Consultant Clinic, of this or another Health Care Provider

25 Admission via Mental Health Crisis Resolution Team

2A Accident and Emergency Department of another provider where the PATIENT had not been admitted

2B Transfer of an admitted PATIENT from another Hospital Provider in an emergency

2C Baby born at home as intended

2D Other emergency admission

28 Other means, examples are:

- admitted from the Accident and Emergency Department of another provider where they had not been admitted
- transfer of an admitted PATIENT from another Hospital Provider in an emergency
- baby born at home as intended

Note: New Admission Method codes 2A, 2B, 2C and 2D were introduced from 2013-2014 to replace the single code 28 “Emergency Admission Other Means”.

7.2 Appendix 2: ICD10 Codes Relating to Neuromuscular Conditions

Code	Description
G12	Spinal muscular atrophy and related syndromes
G12.0	Infantile spinal muscular atrophy, type I (Werdnig-Hoffman)
G12.1	Other inherited spinal muscular atrophy Progressive bulbar palsy of childhood (Fazio-Londe) Spinal muscular atrophy Adult form Childhood form, type II Distal Juvenile form, type III (Kugelberg-Welander) Scapuloperoneal form
G12.8	Other spinal muscular atrophies and related syndromes
G12.9	Spinal muscular atrophy, unspecified
G13	Systemic atrophies primarily affecting central nervous system in diseases classified elsewhere
G13.0	Paraneoplastic neuromyopathy and neuropathy Carcinomatous neuromyopathy (COO-C97+) Sensorial paraneoplastic neuropathy (Denny Brown) (COO-D48+)
G60	Hereditary and idiopathic neuropathy
G60.0	Hereditary motor and sensory neuropathy Disease: Charcot-Marie-Tooth Dejerine-Sottas Hereditary motor and sensory neuropathy, types I-IV Hypertrophic neuropathy of infancy Peroneal muscular atrophy (axonal type) (hypertrophic type) Roussy_Levy syndrome
G60.1	Refsum's disease
G60.2	Neuropathy in association with hereditary ataxia
G60.3	Idiopathic progressive neuropathy
G61	Inflammatory polyneuropathy
G61.0	Guillan-Barre syndrome Acute (post) infective polyneuritis
G61.1	Serum neuropathy
G61.8	Other inflammatory polyneuropathies
G61.9	Inflammatory polyneuropathy, unspecified
G62	Drug-induced polyneuropathy
G62.1	Alcoholic polyneuropathy
G62.2	Polyneuropathy due to other toxic agents
G62.8	Other specified polyneuropathies Radiation induced polyneuropathy
G62.9	Polyneuropathy, unspecified Neuropathy NOS
G63	Polyneuropathy in disease classified elsewhere

G63.0	Polyneuropathy in infectious and parasitic diseases classified elsewhere Polyneuropathy in: Diphtheria (A36.8+) Infectious mononucleosis (B27- +) Leprosy (A30 - +) Lyme disease (A69.2+) Mumps (B26.8+) Postherpatic (B02.2+) Syphilis, late (A50.4+) Congenital syphilis, late (A50.4+) Tuberculosis (A17.8+)
G63.1	Polyneuropathy in neoplastic disease (C00-D48+)
G63.2	Diabetic polyneuropathy
G63.3	Polyneuropathy in other endocrine and metabolic disease (E00-EO7+, E15-E16+, E20 –E34+, E70-E89+)
G63.4	polyneuropathy in nutritional deficiency (E40 –E64+)
G63.5	Polyneuropathy in systemic connective tissue disorders (M30 –M35+)
G63.6	Polyneuropathy in other musculoskeletal disorders (M00 –M25+,M40-M96+)
G63.8	Polyneuropathy in other diseases classified elsewhere Uraemic neuropathy (N18.8+)
G70	Myasthenia gravis and other myoneural disorders (excludes botulism and transient neonatal myasthenia gravis)
G70.0	Myasthenia gravis
G70.1	Toxic myoneural disorders
G70.2	Congenital and developmental myasthenia
G70.8	Other specified myoneural disorders
G70.9	Myoneural disorder, unspecified
G71	Primary disorders of muscles (excludes: arthrogryposis multiplex congenital (Q74.3), metabolic disorders (E70 – E90), myositis (M60 -)
G71.0	Muscular dystrophy Autosomal recessive, resembling Duchenne or Becker Benign (Becker)benign scapuloperoneal with early contractures (Emery-Dreifuss) Distal Facioscapulohumeral Limb-girdle Ocular Oculopharyngeal Scapuloperoneal Severe (duchenne) Excludes:congenital muscular dystrophy with specific morphological abnormalities of the muscel fibre (G71.2)

G71.1	Myotonic disorders Dystrophia myotonia (Steinert) Myotonia Chondrodystrophic Drug-induced Symptomatic Myotonia congenital NOS Dominant (Thomsen) Recessive (Becker) Neuromyotonia (Isaacs) Paramyotonia congenital Pseudomyotonia
G71.2	Congenital myopathies Congenital muscular dystrophy NOS With specific morphological abnormalities of the muscle fibre Disease Central core Minicore Multicore Fibre-type disproportion Myopathy: Myotubular (centronuclear) Nemaline
G71.3	Mitrochondrial myopathy, not elsewhere classified
G71.8	Other primary disorder of muscle
G71.9	Primary disorder of muscle, unspecified myopathy NOS
G72	Other myopathies Excludes: Arthrogryposis multiplex congenitia (Q74.3) Dermatopolymyositis (M33 -) Ischaemia infarction of muscle (M62.2) Myositis (M60 -) Polymyositis (M33.2)
G72.0	Drug-induced myopathy
G72.1	Alcoholic myopathy
G72.2	Myopathy due to other toxic agents
G72.3	Periodic paralysis Periodic paralysis (familial): Hyperkalaemic Hypokalaemic Myotonic normokalaemic
G72.4	Inflammatory myopathy, not elsewhere classified
G72.8	Other specified myopathies
G72.9	Myopathy, unspecified
M33	Dermatopolymyositis
M33.0	Juvenile dermatomyositis
M33.1	Other dermatomyositis
M33.2	Polymyositis
M33.9	Dermatopolymyositis, unspecified

M60	Myositis
M60.0	Infective myositis tropical pyomyositis
M60.1	Interstitial myositis
M60.2	Foreign body granuloma of soft tissue, not elsewhere classified Excludes: foreign body granuloma of skin and subcutaneous tissue (L92.3)
M60.8	Other mysositis
M60.9	Myositis, unspecified
M61	Calcification and ossification of muscle
M61.0	Myositis ossificans traumatic
M61.1	Myositis ossificans preogressive Fibrodysplasia ossificans pprogressive
M61.2	Paralytic calcification and ossification of muscle Myositis ossificans associated with quadriplegia or paraplegia
M61.3	Calcification and ossification of muscles associated with burns Myositis ossificans associated with burns
M61.4	Other calcification of muscle Excludes:calcific tendinitis (M65.2) of shoulder (M75.3)
M61.5	Other ossification of muscle
M61.9	Calcification and ossification of muscle, unspecified
G73	Disorders of myoneural junction and muscle in disease classified elsewhere
G73.0	Myasthenic syndromes in endocrine disease Myasthenic syndromes in: diabetic amyotrophy (E10 – E14+ with common fourth character.4) thyrotoxicosis (hyperthyroidism) (E05 - +)
G73.1	Eaton-Lambert syndrome (C80+)
G73.2	Other myasthenic syndromes in neoplastic disease (C00-D48+)
G73.3	Myasthenic syndromes in other disease classified elsewhere
G73.4	Myopathy in infectious and parasitic disease classified elsewhere
G73.5	Myopathy in endocrine diseases Myopathy in : hyperparathyroidism (E21.0-E21.3+) thyrotoxic myopathy (E05-+)
G73.6	Myopathy in: glycogen storage disease (E74.0+) lipid storage disorders (E75-+)
G73.7	Myopathy in other disease classified elsewhere Myopathy in: Rheumatoid arthritis Scleroderma (M34.8+) Sicca syndrome (Sjogren) (M35.0+) Systemic lupus erythematosis (M32.1+)

E74.0	Glycogen storage diseases Cardiac glycogenosis Disease: Andersen Cori Forbes Hers McArdle Pompe Tauri Von Gierke Liver phosphorylase deficiency
E74	Other disorders of carbohydrate metabolism.

7.3 Appendix 3: Expert consensus criteria for preventable admission (reproduced from (1))

7.2.1 Known potentially preventable complication of neuromuscular disease

- Chest infection
- Falls without fracture/injury
- Falls with fracture/injury
- Cardiac failure/arrhythmia in patients with neuromuscular disease at risk of cardiomyopathy
- Respiratory failure in patients at risk neuromuscular disease
- Other neuromuscular disease specific avoidable complication eg myasthenia relapse

7.2.2 Immunosuppression compliance failure

7.2.3 Recognised immunosuppression complications

7.2.4 Evidence of a previously agreed emergency plan not followed documented in the notes

7.2.5 Documentation of contact with a healthcare professional (in the week) prior to the unplanned admission

7.2.6 Recent recurrent attendances to and direct discharge from A &E without appropriate onward referral to neurology, neuromuscular or therapy service

7.2.7 Delayed discharge from hospital from a recent prior admission

7.2.8 Early readmission to hospital with an existing or new avoidable problem related to the neuromuscular disorder

8 References

1. Korkodilos M, Hajioff S, Gardner C, Overett S, Ibrahim S, Jaffer F, et al. Unplanned Admissions of Neuromuscular Patients 2012 [Available from: http://www.cnmd.ac.uk/documents/AIAU_NMD_Emg_Adm_Audit_2012.pdf.
2. MDUK. Neuromuscular condition prevalence 2010 [Available from: http://www.musculardystrophyuk.org/information-for-professionals/nhs-commissioners/resources-for-nhs-commissioners/neuromuscular-condition-prevalence/.
3. MDUK. Building on the Foundations: Invest to Save improving services and reducing costs. 2011.