



Audit, Information and Analysis Unit

Unplanned admissions of neuromuscular patients

a collaborative audit

Undertaken in conjunction with:

- ▲ London SCG
- ▲ East of England SCG
- ▲ South East Coast SCG
- ▲ South Central SCG
- ▲ Queen Square NMD Centre

On behalf of:

East of England, London and South East Coast
Specialised Commissioning Groups

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Executive summary

Introduction

Neuromuscular diseases are a heterogeneous group of over 60 rare conditions, which affect the muscles or their control. Neuromuscular conditions can be genetic or acquired, are prevalent in all ethnicities and range widely in severity. Most are progressive in nature, often leading to muscle weakness and disability; for most there are no effective treatments or cures. Most neuromuscular disease services are commissioned by regional Specialised Commissioning Groups (SCGs); the National Specialised Commissioning Team commissions a small number on a national basis. There are a number of specialist centres for treating patients with neuromuscular diseases in England and services are also provided at different levels at other hospitals and in community settings.

Unplanned or emergency admissions are felt to be a significant problem nationally for patients with neuromuscular conditions, adversely affecting the quality and experience of care received by the patient, impacting detrimentally on the patient's health, leading to an increased length of stay and unnecessary costs to the NHS.

Aims

An audit to review unplanned/emergency admissions of adults and children with neuromuscular diseases in the London, East of England, South East Coast and South Central regions was developed to understand the reasons for the unplanned admissions, whether these admissions were preventable and if so the nature of the intervention required.

Methodology

This was a retrospective case note audit of admissions of adults and children with neuromuscular diseases in the London, East of England, South East Coast and South Central regions for the 30 month period between the 1st January 2009 and the 30th June 2011.

An audit tool for data collection was designed, piloted and validated by the Neuromuscular Clinical Fellow and the Audit, Information and Analysis Unit project coordinator with input from clinicians and commissioners. The key audit question was whether or not the admission was preventable but other areas of interest were length of stay, whether or not the patient was known to a neuromuscular service and had an emergency admission plan and, once treated, whether there was a delay in discharge.

In the absence of national standards, consensus criteria for a potentially preventable admission were developed by the Clinical Lead in conjunction with an expert group of neuromuscular disease consultants at the Medical Research Council (MRC) Centre for Neuromuscular Diseases.

Of the Trusts who were invited, 12 agreed to participate in this study and provided access to patient notes to the Clinical Fellow.

Results

- In total 395 patients were identified as having an unplanned or emergency admission; data were collected on 576 separate admissions of these patients during the audit timeframe.

Patient demographics

- More men (54.4%, 215/395) were admitted than women.
- The audit population ranged from birth to 96 years with a median age of 61 years.
- Most patients (65.1%, 257/395) were White.
- Only 16.2% (64/395) patients were known to a neuromuscular service at the first admission. Seven of these patients had an emergency plan.
- Of patients with a known neuromuscular condition, the most common condition was a neuromuscular junction disorder (21.5%, 55/256).
- Just over a third of patients had other admissions in the year prior to the data collection period.

Unplanned admissions during the audit period

- Most admissions (65.3%, 376/576) were to a hospital with a neuromuscular service.
- Three quarters of patients had one admission, 18 patients (4.6%, 18/395) had four or more admissions in the audit period.
- Of the total admissions, most (56.8%, 327/576) could not be prevented. This was in contrast to admissions related to a known neuromuscular condition where most of these admissions (68.7%, 156/227) could or could possibly have been prevented.
- Of the 524 measures that were identified that could have prevented an admission, most of these (60.1%, 315/524) were through patient surveillance, access to neuromuscular services and having an emergency plan.
- Most admissions were not preventable due to first presentation of symptoms (33.9%, 111/327), acute presentation (29.4%, 96/327) and the patient required inpatient management (23.5%, 77/327).

- There were no marked differences in preventability in patients who were admitted to a hospital with a specialist neuromuscular service (40.5%, 152/376) compared to those who were admitted to a hospital without a specialist service (45.7%, 92/200).
- Most admissions (59.5%, 343/576) were via the Accident and Emergency department.
- Over half of admissions (53.1%, 306/576) were under the care of General Medicine.
- No documented neurology review took place for most admissions (58.3%, 336/576). In the 193 admissions where a neurology review took place, most (88.1%, 107/193) were carried out by a Consultant.
- Length of stay ranged from one to 340 days, with a median length of stay of six days. There was little difference in the length of stay between the cohort of admissions that were considered preventable (median length of stay 6.5 days) and those that were not (median length of stay 6 days).
- Eleven percent of admissions included an admission to the Intensive Care Unit (ICU). Length of stay ranged from one to 166 days with a median of 7 days.
- Eighteen percent of patients were considered to have a delayed discharge most commonly due to a delay in accessing investigations or a clinical opinion (41.9%, 44/132).
- For most admissions (77.1%, 444/576) the patient was discharged home.
- After 12.5% (72/576) of admissions the patient was linked in with specialist neuromuscular services for follow up. For 20.5% (118/576) of admissions this was not appropriate as the reason for admission was not linked to a neuromuscular condition or the patient had died.

Executive summary

Conclusions

This study has described the experiences of a sample of patients with a neuromuscular condition and has found that over a third of admissions in this sample were preventable and a further 5% were 'possibly' preventable. This not only places potentially unnecessary stress on patients and their families but also represents a significant opportunity cost to the NHS.

The study has also highlighted measures which could potentially prevent such admissions and commissioners should work with neurology and neuromuscular services to develop integrated referral and management pathways to ensure that all patients with neuromuscular conditions have access to the right care at the right time whether that is in a specialist centre, local hospital or in the community.

Recommendations

- 1 Monitoring of known neuromuscular patients and access to neuromuscular services between clinic appointments should be strengthened. This could be co-ordinated in a more formal process by the service, for example by the clinical nurse specialist.
- 2 The specialist neuromuscular centre should co-ordinate care across different sub-specialities (neuromuscular, cardiac and respiratory). Fragmentation of care across different hospitals should be avoided, where possible, to ensure good communication, avoid conflicting advice and provide an integrated care pathway.
- 3 All patients with a known neuromuscular diagnosis should have a documented emergency plan which specifies a clear point of access for emergency care. This may include telephone access for the patient to the specialist neuromuscular centre during times of worsening health.

- 4 Specialist neuromuscular centres should develop links, preferably with outreach, with local hospitals to enable advice, diagnosis and referral to be managed in a timely fashion. Links should also be improved with local social services to ensure a patient's ongoing needs can be met and prevent delays in discharge due to social issues.
- 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:
 - a Documented referral to the neurology team even if the neuromuscular condition is not the prime reason for admission
 - b Emergency plan on discharge

Health professionals should ensure that there is clear documentation of any review of a patient.

Next steps

- The findings of this study will be presented to:
 - All Party Parliamentary Group for Muscular Dystrophy
 - Pan-Specialised Commissioning Group Neuromuscular Working Group to take the recommendations forward
 - British Myology Society Annual Meeting
- This study will be used to inform the development of a neuromuscular service specification and tools to support the commissioning of neuromuscular services by the Neurosciences Clinical Reference Group.

1

Introduction

1.1 Background

Neuromuscular diseases are a heterogeneous group of over 60 rare conditions, which affect the muscles or their control. There is a lack of epidemiological research in this area and patient numbers for each condition or group of conditions vary widely, but data from the Muscular Dystrophy Campaign suggest that over 70,000 people in the UK are living with a neuromuscular condition¹. Neuromuscular conditions can be genetic or acquired, are prevalent in all ethnicities and range widely in severity. Most are progressive in nature, often leading to muscle weakness and disability; for most there are no effective treatments or cures. Recent improvements in quality of life and increases in life expectancy are due to advances in care and clinical management not novel therapies^{1,2}.

Most neuromuscular disease services are commissioned by regional Specialised Commissioning Groups (SCG); the National Specialised Commissioning Team commissions a small number on a national basis. There are a number of specialist centres for treating patients with neuromuscular diseases in England and services are also provided at different levels at other hospitals and in community settings. The All Party Parliamentary Group (APPG) for Muscular Dystrophy and the Muscular Dystrophy Campaign had become concerned about access to specialist neuromuscular care and the reliance of the specialist centres on charitable funding and their Lead Clinicians which it felt left them vulnerable. A parliamentary inquiry was launched in 2008 and culminated in *Access to Specialist Neuromuscular Care: The Walton Report*², which shone a spotlight on current provision and called for prompt action from the NHS.

Following the Walton Report the SCGs developed a national work programme to implement its recommendations; this is being led by the East of England SCG. In 2011 it was agreed that unplanned admissions would be an important area for further work. This was because unplanned or emergency admissions were felt to be a significant problem nationally for patients with neuromuscular conditions, adversely affecting the quality and experience of care received by the patient, impacting detrimentally on the patient's health, leading to an increased length of stay, to a deterioration in the patient's condition that necessitated the admission and incurring significant and unnecessary

costs to the NHS (estimated at over £28 million in the London, East of England, South East Coast and South Central regions³). It was thought that focused interventions and investment to ensure all neuromuscular patients are connected to a specified neuromuscular service and therefore receive expert monitoring and care and for an identified subset of appropriate patients having an agreed emergency plan in place to deal with emergencies in a planned and effective manner could potentially improve the patient experience, reduce the negative impact on the patient's health and mitigate the costs to the NHS.

An audit to review unplanned/emergency admissions of adults and children with neuromuscular diseases in the London, East of England, South East Coast and South Central regions was developed. An unplanned admission is an admission that is not predicted and happens at short notice because of perceived clinical need⁴. An initial scoping exercise was carried out and demonstrated that approximately £9 million of unplanned activity took place in 2009/10 for London residents. Further information was required to understand the reasons for the unplanned admissions, whether these admissions were preventable and if so the nature of the intervention required.

1.2 Aims

This study set out to:

- Identify unplanned or emergency admissions among patients with neuromuscular disease in London, East of England, South East Coast and South Central regions.
- Determine which admissions were related to a patient's neuromuscular condition and of these, which were likely to have been preventable, the reasons behind this and to understand what measures, if any, may have prevented these admissions.
- Understand the proportion of patients in the sample who were known to a neuromuscular service and the proportion with emergency plans in place.
- Gather information on admissions such as length of stay and reasons for delays in discharge.
- Compare the characteristics of unplanned admissions at hospitals with a specialist neuromuscular service and those without such a service.

2

Methods

This was a retrospective case note audit of admissions of adults and children with neuromuscular diseases in the London, East of England, South East Coast and South Central regions for the 30 month period between the 1st January 2009 and the 30th June 2011.

Patients were identified by the information teams at each SCG using secondary user services (SUS) data to identify admissions with an unplanned admission code and a neuromuscular ICD-10 code in either the primary or secondary diagnosis field.

A project team was organised that consisted of the lead clinician, two senior commissioners from the London SCG, the AIAU project coordinator and a Neuromuscular Clinical Fellow who was seconded to the project to review the case notes and carry out the data collection.

An audit tool for data collection was designed, piloted and validated by the Neuromuscular Clinical Fellow and the AIAU project coordinator with input from clinicians and commissioners. The key audit question was whether or not the admission was preventable but other areas of interest were length of stay, whether or not the patient was known to a neuromuscular service and had an emergency admission plan and, once treated, whether there was a delay in discharge.

In the absence of national standards, consensus criteria for a potentially preventable admission were developed by the Clinical Lead in conjunction with an expert group of neuromuscular disease consultants at the MRC Centre for Neuromuscular Diseases.

The criteria against which an admission was assessed as preventable are listed below. If one or more of the criteria were documented to be present on case note review by the Neuromuscular Clinical Fellow the admission was considered to be potentially preventable. The Clinical Fellow visited each participating site where actual case notes had been collated in collaboration with the local consultant team. Data obtained directly from case note review were entered immediately on site into the lap-top based electronic audit tool. Electronic data on the encrypted laptop were then physically transported to the data repository team base and downloaded securely. Analysis was undertaken by an independent data analyst separate from the Clinical Fellow and team. All necessary data protection, audit and governance regulations were strictly adhered to.

- 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
- Immunosuppression compliance failure
- Recognised immunosuppression complications
- Evidence of a previously agreed emergency plan not followed documented in the notes
- Documentation of contact with a healthcare professional (in the week) prior to the unplanned admission
- Recent recurrent attendances to and direct discharge from A&E without appropriate onward referral to neurology, neuromuscular or therapy service
- Delayed discharge from hospital from a recent prior admission
- Early readmission to hospital with an existing or new avoidable problem related to the neuromuscular disorder

2.1 Timescales

Hospital visits for data collection were carried out from July 2011 until January 2012. Interim results based on data collected up to the end of October were presented at a neuromuscular workshop held by the East of England SCG on the 1st December 2011.

2.2 Participation

There are ten NHS Trusts with specialist neuromuscular services in the East of England, London, South Central and South East Coast regions each with associated outreach hospitals. An initial search of SUS data identified a number of other Trusts which had admissions with a neuromuscular ICD-10 code in either the primary or secondary diagnosis field. Appendix 1 lists all Trusts that were invited to participate in the study and Appendix 2 lists all associated outreach hospitals.

Of the Trusts who were invited, the following 12 agreed to participate in this study and provided access to patient notes to the Clinical Research Fellow:

- Barts Health NHS Trust (Royal London Hospital and Whipps Cross Hospital)
- Brighton and Sussex University Hospitals NHS Trust
- The North West London Hospitals NHS Trust (Central Middlesex Hospital and Northwick Park Hospital)
- Guy's and St Thomas' NHS Foundation Trust (Evelina Children's Hospital)
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Homerton University Hospital NHS Foundation Trust
- Imperial College Healthcare NHS Trust (Charing Cross Hospital and Hammersmith Hospital)
- Oxford University Hospitals NHS Trust (John Radcliffe Hospital)
- Barking, Havering and Redbridge University Hospitals NHS Trust (King George Hospital and Queen's Hospital)
- University College London Hospitals NHS Foundation Trust
- Royal Free London NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust

The remaining Trusts either declined to participate because of time or administration support constraints or did not respond to the request within the predetermined time scale.

3

Cases audited

In total 395 individual patients were identified as having had unplanned or emergency admissions between the 1st January 2009 and 30th June 2011 and were included in the dataset. For these patients data were collected on 576 separate admissions during the audit time frame and were included in the analysis for this report.

Table 1 – Number of admissions included in the audit by NHS Trust and site

Trust	Hospital	Number of admissions
Barts Health NHS Trust	Royal London*	22
	Whipps Cross**	28
Brighton and Sussex University Hospitals NHS Trust		66
Barking, Havering and Redbridge University Hospitals NHS Trust	King George	2
	Queen's	30
The North West London Hospitals NHS Trust	Central Middlesex	1
	Northwick Park	57
Guy's and St Thomas' NHS Foundation Trust*	Evelina Children's	6
Great Ormond Street Hospital for Children NHS Foundation Trust*		7
Homerton University Hospital NHS Foundation Trust		16
Imperial College Healthcare NHS Trust*	Charing Cross	36
	Hammersmith	10
Oxford University Hospitals NHS Trust*	John Radcliffe	103
University College London Hospitals NHS Foundation Trust (including NHNN)*		37
Royal Free London NHS Foundation Trust*		45
University Hospital Southampton NHS Foundation Trust*		110
Total		576

* Denotes Trusts considered to have a specialist neuromuscular service.

** Barts Health was formed on 1st April 2012 so at the time of data collection Whipps Cross Hospital was not yet part of this NHS Trust.

4

Individual patient level findings

The following analysis is based on the cohort of individual patients rather than on an admission by admission basis. 395 individual patients were found in the audit. For patients with multiple recorded admissions during the audit period, data were taken from the first admission for which data were collected.

4.1 Patient demographics

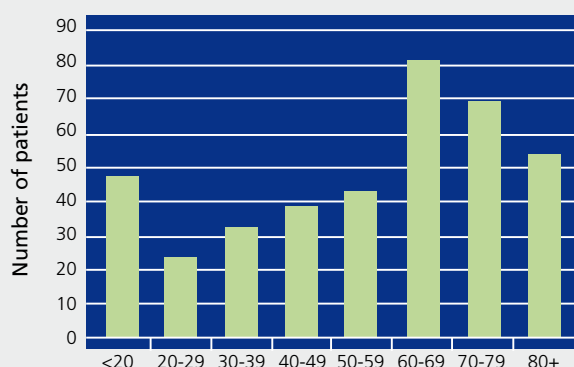
Gender

The audit population was 54.4% male (n=215) and 45.3% female (n=179). For one patient no gender was recorded.

Age

The audit population ranged from birth to 96 years of age with a median age of 61 years. There were no differences between the male and female cohorts. For patients with multiple admissions during the audit period, age was calculated at the time of the first admission during the time for which data were collected.

Figure 1 – Age distribution of audit population



The paediatric cohort (defined for this study as children under the age of 16) made up 10.4% (n=41) of the total population in the audit and are analysed separately in section 6.

Ethnicity

Sixty five percent of the audit population were identified as white (Caucasian) (n=257), 10.6% (n=42) were south Asian, 4.3% (n=17) were black (Afro-Caribbean origin), one patient was from a mixed background and 17.7% were from another ethnic background (n=70). For eight patients (2.0%) ethnicity was not recorded.

Patient region of residence

Just over half of the patients were from London (n=203, 51.4%) and the majority of those were from Primary Care Trusts (PCTs) in north London (n=185, 91.1%). Thirteen percent of patients (n=51) were from the South East Coast region and one patient was from the North East but being treated in London. For 140 patients (35.4%) this information was not recorded including all 129 patients who attended John Radcliffe and Southampton Hospitals and it may be possible patients who attended these two hospitals were all from the South Central region.

4.2 Patient known to a neuromuscular service

This question looks at whether patients are, or have been, under the ongoing care of a neuromuscular service. Of the 395 individual patients, 64 (16.2%) were already known to a neuromuscular service at the first admission for which data were collected, while over three quarters (n=304, 76.9%) were not. 27 patients (6.8%) had confirmed neuromuscular diagnoses but it was not clear from the notes if they were known to a neuromuscular service or not.

Emergency plan

Of the individual patients, 3.0% (n=12) had a documented emergency plan at the first admission for which data were collected while the large majority (n=378, 95.7%) did not. For five patients this information was not recorded.

Of the 64 patients known to a neuromuscular service, seven had an emergency plan (10.9%), 87.5% (n=56) did not and for one patient this information was not recorded.

Individual patient level findings

4.3 Pre-existing neuromuscular condition

Of the individual patients, over a third had no previously known neuromuscular condition at the first admission for which data were collected (n=139, 35.2%). Of these, 120 had a diagnosis or a working diagnosis of neuromuscular disease at discharge and the admission likely constituted a presentation event. Half of these 120 patients had a diagnosis or working diagnosis of Guillain-Barre syndrome at discharge and nine patients (7.5%) had a diagnosis of Myasthenia Gravis.

Of the 139 patients with no known neuromuscular condition at the first admission for which data were collected, 14 went on to have further admissions during the audit period. All of these patients except one had a known neuromuscular condition at these subsequent admissions.

In the remaining cohort of 256 patients the most common neuromuscular condition was a neuromuscular junction disorder, mainly Myasthenia Gravis, (n=55, 21.5%) then unspecified neuropathy (n=40, 15.7%) and diabetic neuropathy (n=31, 12.1%).

Of the 21 patients with a diagnosis of 'other specified neuropathy', 13 were considered to be alcohol related.

Table 2 – Known neuromuscular condition

Neuromuscular condition	Number of patients (%)
Neuromuscular junction disorder	55 (21.5)
Unspecified neuropathy	40 (15.6)
Diabetic neuropathy	31 (12.1)
Other specified neuropathy	21 (8.2)
Muscular Dystrophy	20 (7.8)
Inflammatory myositis	15 (5.8)
Myotonic disorders	13 (5.1)
Inflammatory neuropathy	12 (4.7)
Spinal Muscular Atrophy	9 (3.5)
Hereditary neuropathy	7 (2.7)
Mitochondrial myopathy	5 (1.9)
Other myopathy	5 (1.9)
Neuropathy secondary to connective tissue disorder	4 (1.6)
Metabolic disorder	4 (1.6)
Congenital myopathy	3 (1.2)
Myopathy secondary to connective tissue disorder	3 (1.2)
Unspecified myopathy	3 (1.2)
Drug induced myopathy	2 (0.8)
Other	2 (0.8)
Unclear/unknown	2 (0.8)
Total	256

Despite having a known neuromuscular condition, 164 patients (64.0%) were not recorded as being known to a neuromuscular service.

Individual patient level findings

4.3.1 Previous admissions

Just over a third of the individual patients were recorded as having had other admissions in the year prior to the data collection period (n=140, 35.4%) while 43.5% (n=172) had not. However for 21.0% of patients (n=83) this information was either not clear from the notes or was not recorded.

Of the patients who had had previous admissions (n=140), 28 (20.0%) did not have a known neuromuscular condition and almost three quarters (n=103, 73.6%) were not recorded as being known to a neuromuscular service.

5

Unplanned admissions during the audit period

In total data on 576 separate unplanned admissions from the 1st January 2009 to the 30th June 2011 were collected and analysed for this report. Almost two thirds of admissions in this sample (n=376, 65.3%) were to a hospital with a specialist neuromuscular service while just over a third (n=200, 34.7%) were to a hospital with no neuromuscular service (please see Table 1 for a list of Trusts with a specialist neuromuscular service).

The admissions were not evenly spread throughout the audit period; 29.3% (n=169) occurred in 2009, 57.2% (n=330) occurred in 2010 and 13.4% (n=77) occurred in the first six months of 2011.

When making inference as to what neuromuscular services can do in the prevention of admissions, whether or not the admission is potentially related to neuromuscular disease may be a factor. For this reason several of the analyses below were, in addition to being carried out on the basis of all admissions, repeated looking only at admissions deemed to be related to a pre-existing neuromuscular condition. These data have only been included where they shed particular light or where they are markedly different from the all admissions analysis.

5.1. Number of admissions per patient

Three quarters of patients (n=296) had one unplanned admission during the audit period (Table 3).

Table 3 - Number of admissions per patient

Number of admissions	Number of patients (%)
One	296 (74.9)
Two	55 (13.9)
Three	26 (6.6)
Four	11 (2.8)
Five	2 (0.5)
Six or more	5 (1.3)
Total	395

5.2. Was the final diagnosis potentially secondary to neuromuscular condition

Of the 576 admissions, 227 (39.4%) were judged to be potentially related to the patient's underlying neuromuscular condition, 201 (34.9%) were not related to the patient's underlying neuromuscular condition.

It should be noted that some admissions were related to a disease process, such as diabetes or alcohol abuse, that can lead to a neuromuscular disease and were not related to the neuromuscular sequelae of the parent disease but rather to some other presentation. An example of this might be hypoglycaemia in a patient with diabetes mellitus who also happens to have diabetic neuropathy.

The remaining 148 admissions did not have a neuromuscular diagnosis prior to admission and cannot therefore be seen as related or unrelated to a prior diagnosis. One hundred and twenty (81.6%) of these admissions had a diagnosis or a presumptive diagnosis of neuromuscular disease at discharge.

5.3. Was the admission preventable?

Of the total admissions, 37.5% (216) of admissions were considered to be preventable based on the audit criteria and 4.9% (n=28) were 'possibly' preventable. Over half were not considered to be preventable (n=327, 56.8%) and in five cases this could not be determined from the notes. The picture for admissions related to a known neuromuscular condition is significantly different in that, of the 227 neuromuscular related admissions 143 (63.0%) were judged preventable, 5.7% (13) possibly preventable and 29.5% (67) not preventable (Table 4).

Table 4 - Preventability of admission, all admissions vs. admissions related to known neuromuscular condition

Number of admissions	All admissions (%)	Neuromuscular related admissions (%)
Yes	216 (37.5)	143 (63.0)
Possibly	28 (4.9)	13 (5.7)
No	327 (56.8)	67 (29.5)
Could not be determined	5 (0.9)	4 (1.8)
Total	576	227

In total 244 admissions were considered to be preventable or possibly preventable. Table 5 summarises the measures that could have prevented the admission, for some admissions more than one measure could have prevented it. There were 524 measures that could have prevented all admissions and 381 that could have prevented admissions of patients with known neuromuscular conditions.

The most frequent potential preventative measures were surveillance of a patient's condition, access to neuromuscular services and having an emergency plan (n=315, 60.1%). The reasons for prevention were similar in all preventable admissions and in those of patients with known neuromuscular conditions (Table 5).

Table 5 - Measures which could prevent unplanned or emergency admissions

Intervention / measure	All preventable admissions (%)	Preventable neuromuscular related admissions (%)
Surveillance of patient's condition	139 (26.5)	114 (29.9)
Access to neuromuscular services	116 (22.1)	98 (25.7)
Having an emergency plan	60 (11.5)	59 (15.5)
Access to liaison with other services*	41 (7.8)	13 (3.4)
Prevent delay in referral to a neurology service	32 (6.1)	11 (2.9)
Provision of equipment (including orthotics)	34 (6.5)	34 (8.9)
Prevent delay in initial diagnosis	29 (5.5)	8 (2.1)
Patient/parent education	23 (4.4)	18 (4.7)
Physiotherapy referral/review	22 (4.2)	16 (4.2)
Monitoring of repeat admissions for recurrent symptoms	15 (2.9)	4 (1.0)
Access to social services	6 (1.1)	1 (0.3)
Access to alcohol/substance abuse services	3 (0.6)	0 (0.0)
Having a discharge plan	3 (0.6)	4 (1.0)
Better transition to adult care	1 (0.2)	1 (0.3)
Total	524	381

*Other services include respiratory, cardiology, palliative care, oncology, psychiatry, diabetes, urology, ophthalmology and care of the elderly.

Unplanned admissions during the audit period

Of the admissions that were considered to be non-preventable (327), the main reason for this was because it was the first presentation of symptoms (n=111, 33.9%). Other common reasons were because it was an acute presentation (n=89, 27.2%) and because the patient required inpatient care and/or investigations (n=77, 23.5%) (Table 6).

Non-preventable admissions related to an underlying neuromuscular condition are distributed somewhat differently (Table 6).

Table 6 - Reasons why unplanned or emergency admissions were not preventable

Reason for admission	All non-preventable admissions (%)	Neuromuscular related non-preventable admissions (%)
First presentation of symptoms	111 (33.9)	0 (0.0)
Acute presentation	96 (29.4)	11 (16.4)
Required inpatient management	77 (23.5)	33 (49.3)
Needed tests to exclude a diagnosis	17 (5.2)	9 (13.4)
Required emergency surgery/ intervention/ opinion	10 (3.1)	3 (4.5)
Failed emergency plan	9 (2.8)	4 (6.0)
Followed emergency plan	5 (1.5)	7 (10.4)
Trauma	1 (0.3)	0 (0.0)
Failed discharge	1 (0.3)	0 (0.0)
Total	327	67

5.4. Preventable and non-preventable admissions by hospital type

The admissions were further broken down into those that were to a hospital with a specialist neuromuscular service (n=376) and those to hospitals without (n=200).

There were no marked differences between the two cohorts: although fewer admissions into hospitals without a specialist service were considered to be unavoidable (53% vs 59% at hospitals with a specialist neuromuscular service) this was more a reflection of a greater number of those admissions which were judged 'possibly' preventable (7% vs 3%) rather than a greater number of preventable cases (39% vs 37%).

Table 7 - Admissions by hospitals with and without a specialist neuromuscular service

	Hospitals with a specialist neuromuscular service (%)	Hospitals without a specialist neuromuscular service (%)
Preventable	139 (37.0)	77 (38.5)
'Possibly' preventable	13 (3.5)	15 (7.5)
Not preventable	221 (58.8)	106 (53.0)
Could not be determined	3 (0.8)	2 (1.0)
Total	376	200

It should be noted that even where patients were admitted to a hospital with a specialist neuromuscular service it may not have been the service they were known to but may have been the most convenient or appropriate hospital at the time of admission. There were 85 admissions to a hospital with a specialist service where the patient was known to neuromuscular services but of these over a quarter (n=23, 27.1%) were not into the hospital where the patient was known.

5.5. Admission characteristics

5.5.1. Admission route

Most (59.5%, n=343) of admissions were via Accident and Emergency (A&E). Other admission routes were direct referrals from a GP (n=85, 14.8%) and transfers from another hospital (n=72, 12.5%) (Table 8).

	Number of admissions (%)
A&E	343 (59.5)
GP	85 (14.8)
Transfer from other hospital	72 (12.5)
Clinic	54 (9.4)
Other department/specialty	10 (1.7)
Home	2 (0.3)
Other*	4 (0.7)
Not known or recorded	6 (1.1)
Total	576

*'Other' admission routes were: two referrals from private ophthalmologists, one self-referral and one repatriation from Europe.

5.5.2. Admitting specialty

General medicine accounted for over half of admissions (n=306, 53.1%) but admissions to other specialties varied widely. 14.9% (n=86) of admissions were to neurosciences services and 10.9% of admissions were to paediatric services (n=63). In five cases the admitting specialty was not recorded (Table 9).

Table 9 - Admitting specialty

Service	Number of admissions (%)
General Medicine	306 (53.1)
Neurosciences	86 (14.9)
Neurology	80
Neuro intensive care	4
Neuro-ophthalmology	2
Paediatrics	63 (10.9)
Paediatrics	51
Paediatric neurology	4
PICU	4
Paediatric HDU	2
Paediatric A&E	1
NICU	1
Surgery	32 (5.5)
General surgery	29
Vascular surgery	3
Trauma and Orthopaedics	16 (2.8)
A&E	13 (2.2)
Intensive care	9 (1.6)
Rheumatology	8 (1.4)
Cardiology	6 (1.0)
Respiratory	5 (0.9)
Care of the elderly	5 (0.9)
Oncology	4 (0.7)
Gastroenterology	3 (0.5)
Stroke	3 (0.5)
Renal	2 (0.3)
Haematology	2 (0.3)
Hepatology	1 (0.2)
Ear, Nose and Throat	1 (0.2)
Acute medicine	1 (0.2)
Gynaecology	1 (0.2)
Dermatology	1 (0.2)
Ophthalmology	1 (0.2)
Plastics	1 (0.2)
Urology	1 (0.2)
Not recorded	5 (0.9)
Total	576

Unplanned admissions during the audit period

5.5.3. Coded discharge diagnosis for the admission

All hospital admissions are coded using the International Classification of Diseases (10th revision) coding system (ICD-10), which is the international standard for hospital diagnostic classification. This enables the use of such data for epidemiological, clinical and quality purposes both nationally and internationally and, in the NHS in England, is used along with other coding systems to derive the health related group (HRG) code which determines payment. Admissions may have more than one code depending on primary and secondary diagnoses and for this study the ICD-10 code relating to the neuromuscular condition was collected for each admission. These data were not available for 113 admissions.

The single most common code range used was G62 other polyneuropathies (n=114, 24.6%) followed by G70 Myasthenia Gravis and other myoneural disorders (n=101, 21.8%) (Table 10).

Table 10 - ICD-10 code and descriptor for admissions

Code and descriptor	Number of admissions (%)
G62 Other polyneuropathies	114 (24.6)
G70 Myasthenia Gravis and other myoneural disorders	101 (21.8)
G61 Inflammatory polyneuropathy	63 (13.6)
G71 Primary disorders of muscles	57 (12.3)
G72 Other myopathies	26 (5.6)
M33 Dermatopolymyositis	26 (5.6)
G63 Polyneuropathy in diseases classified elsewhere	18 (3.9)
G12 Spinal muscular atrophy and related syndromes	15 (3.2)
M60 Myositis	15 (3.2)
G60 Hereditary and idiopathic neuropathy	10 (2.2)
E74 Glycogen storage disorders	7 (1.5)
G13 Systemic atrophies primary affecting central nervous systems in diseases classified elsewhere	4 (0.9)
G73 Disorders of myoneural junction and muscle in diseases classified elsewhere	4 (0.9)
M61 Calcification and ossification of muscle	1 (0.2)
G61 & G62	1 (0.2)
G61 & G72	1 (0.2)
Total	463

Of the two patients with two ICD-10 descriptors, one had Guillain-Barre Syndrome and an unspecified peripheral neuropathy and the other had Guillain-Barre Syndrome with unspecified myopathy.

5.5.4. Emergency plan

There were 12 patients who had a documented emergency plan at the first admission during the audit period for which data were collected and another four patients had one set up during the audit period to give a total of 16 patients with a documented emergency plan. In total these patients had 25 admissions during the audit period. The plan was followed in 19 of these cases and for one admission it was followed partially. For two admissions the plan was not followed and in three cases this information was not available.

5.5.5. Neurology review

No documented neurology review took place in the majority of admissions (n=336, 58.3%) and in 47 cases (8.2%) this was either not clear from the notes or not recorded.

In the 193 admissions where a neurology review did take place most patients were seen by a Consultant (n=170, 88.1%).

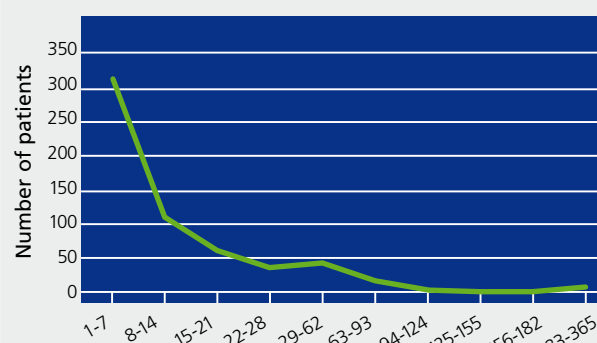
Table 11 - Grade of staff member who carried out neurology review

Staff member	Number of patients (%)
Neurology Consultant	107 (55.4)
Neuromuscular Consultant	63 (32.6)
Neurology Specialist Registrar (SpR)	19 (9.8)
Myasthenia Gravis nurse	1 (0.5)
Total	193

5.6. Length of stay and discharge

Total length of stay ranged from one to 340 days with a median length of stay of six days. Over half of admissions (n=312, 54.1%) resulted in a length of stay of one week or less and 18.1% (n=104) lasted one day. For 11 admissions length of stay could not be calculated as the date of discharge was not recorded. Total bed days amounted to 8,556 for all admissions and 3,477 for admissions related to a known neuromuscular condition.

Figure 2 - Length of stay (n=576)



5.6.1. Preventable admissions

Admissions that were considered to be preventable (n=216) accounted for 3,074 bed days (36% of the total bed days) and included one admission with a length of stay of 340 days and three with a length of stay of over 100 days. The median length of stay was seven days. For four admissions the length of stay could not be calculated as the date of discharge was not recorded.

There was little difference in the lengths of stay between the cohort of admissions which were considered to be preventable and those which were not (median 6.5 vs 6 days) although the unavoidable admissions had a slightly higher percentage of stays of only one day (20% vs 17%).

It should be noted that, of the total preventable bed days, 72% (2,204) were among admissions related to an underlying neuromuscular condition. In terms of preventable admissions numbers, 66% are related to an underlying neuromuscular condition.

Unplanned admissions during the audit period

5.6.2. Hospitals with and without a specialist neuromuscular service

There was little difference in lengths of stay between hospitals with and without a specialist neuromuscular service (median 7 vs 6 days).

5.6.3. Admission to an intensive care unit

A number of admissions included an admission to an intensive care unit (ICU) (n=63, 10.9%). Length of stay on ICU ranged from one to 166 days with a median of 7 days (however length of stay was only available in 41/63 cases).

Of the 63 admissions with an ICU spell, a third were considered to be preventable (n=20, 31.7%), six were possibly preventable (9.5%) and just over half were not preventable (n=34, 54.0%). In three cases this could not be determined from the notes. This is broadly in line with the total admissions. The patient who had a length of stay in ICU of 166 days was considered to have had an unpreventable admission.

In 18 of these admissions (28.6%) the patient was known to a neuromuscular service and for over half (n=33, 52.3%) the admission was related to the patient's neuromuscular condition. This is higher than the percentage seen for the total admissions where 39.4% were related to an underlying neuromuscular condition.

5.6.4. Delayed discharge

Factors affecting discharge were assessed qualitatively on a case by case basis. Eighteen percent of admissions (n=105) were considered to have had a delayed discharge. The most common reason for this was a delay in accessing investigations or a clinical opinion (n=44, 41.9%).

Table 12 - Reasons for delayed discharge

	Number of discharges (%)
Access to investigations/opinion	44 (41.9)
Access to rehab/intermediate care	18 (17.1)
Social care input/package of care	17 (16.2)
Medical complications	13 (12.4)
Accommodation/home equipment	11 (10.5)
Delay in transfer to another hospital	10 (9.5)
Access to other allied health care professionals	4 (3.8)
Access to respite care	3 (2.9)
Access to physiotherapy/occupational therapy	3 (2.9)
Access to orthotics	2 (1.9)
Access to wheelchair services	2 (1.9)
Other*	5 (4.8)
Total	132

Numbers total greater than 105 as some patients had multiple reasons for their delayed discharge.

* 'Other' includes delay in diagnosis; delay in therapy, patient did not feel ready to leave hospital and patient unwilling to accept social care package.

Of these 105 admissions with delayed discharge, over half (n=58, 55.2%) were considered to be preventable or possibly preventable.

Table 13 - Delayed discharge by preventable and non-preventable admissions

	Preventable admissions	Possibly preventable admissions	Non-preventable admissions	Total
Delayed discharge (%)	52 (49.5)	6 (5.7)	47 (44.8)	105
No delayed discharge (%)	151 (35.1)	17 (4.0)	262 (60.6)	430
Not applicable as patient died (%)	8 (32)	5 (20.0)	12 (48.0)	25
Not known from notes (%)	5 (45.5)	0 (0.0)	6 (55.5)	11

*Excludes 5 admissions where it could not be determined whether the admission was preventable or not

5.6.5. Discharge location

In the majority of cases (n=444, 77.1%) the patient was discharged to their home. For 12 discharges this was unclear from the notes or was not recorded (Table 14).

Table 14 - Discharge location

	Number of discharges (%)
Home	444 (77.1)
Transfer to another hospital	49 (8.5)
Transfer back to referring hospital	19 (3.3)
Intermediate care	12 (2.1)
Nursing care	9 (1.5)
Back to residential care	5 (0.9)
Not applicable as patient died	26 (4.5)
Unclear or not recorded	12 (2.1)
Total	576

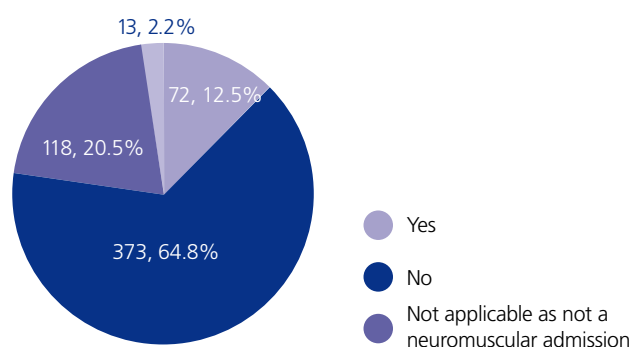
5.7. Specialist follow up

Total length of stay ranged from one to 340 days with a median length of stay of six days. Over half of admissions (n=312, 54.1%) resulted in a length of stay of one week or less and 18.1% (n=104) lasted one day. For 11 admissions length of stay could not be calculated as the date of discharge was not recorded. Total bed days amounted to 8,556 for all admissions and 3,477 for admissions related to a known neuromuscular condition.

5.7.1. Specialist neuromuscular services

After 12.5% (n=72) of admissions the patient was linked in with specialist neuromuscular services for follow up while after almost two thirds the patient was not (n=373, 64.8%). For 20.5% of admissions (n=118) this was not appropriate as the reason for admission was not linked to a neuromuscular condition or the patient had died and in 13 admissions (2.2%) this information was either not clear from the notes or not recorded (Figure 3).

Figure 3 - Patient linked in with specialist neuromuscular services for follow up

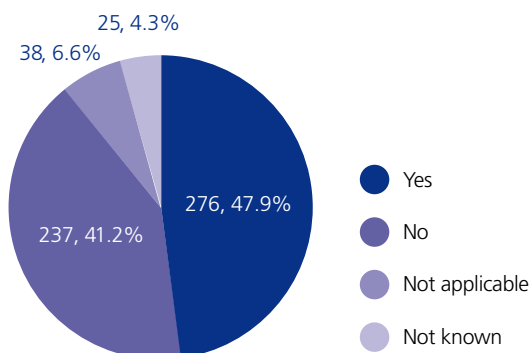


Unplanned admissions during the audit period

5.7.2. Other specialist services

After just under half of admissions (n=276, 47.9%) the patient was linked in with another specialist service for follow up while after 237 (41.2) admissions the patient was not. For 6.6% (n=38) this was not appropriate as the patient was already linked with other services, other specialist services were not required or the patient had died and in 25 cases (4.3%) this information was either not clear from the notes or not recorded (Figure 4).

Figure 4 - Patient linked in with other specialised services for follow up



6

Unplanned or emergency admissions in children

Of the total audit population, 10% (n=41) were under 16 years of age. Data were collected on 66 separate admissions for these patients during the audit period.

6.1. Individual patient data

14 children were recorded as being known to a neuromuscular service at the first admission during the audit period for which data were collected.

Six children had a documented emergency plan in place at the first admission for which data were collected. Seventeen did not have an emergency plan but did not have a neuromuscular diagnosis at the time of admission, while 16 did not have a plan but did have a diagnosis. For two patients this information was not recorded.

Eighteen children did not have a known neuromuscular diagnosis. For the remaining 23 children the most common condition (30.4%, n=7) was Spinal Muscular Atrophy (Table 15).

Table 15 - Known neuromuscular condition for paediatric admissions

Neuromuscular condition	Number of patients (%)
Spinal Muscular Atrophy	7 (30.4)
Muscular Dystrophy	5 (21.7)
Mitochondrial myopathy	4 (17.4)
Metabolic disorder	3 (13.0)
Congenital myopathy	3 (13.0)
Hereditary neuropathy	1 (4.3)
Total	23

6.2. Admissions during the audit period

The majority of patients had one admission during the audit period (n=28, 68.3%). Of the remaining 13 patients:

- Six patients had two admissions.
- Four patients had three admissions.
- Two patients had four admissions.
- One patient had six admissions.

6.2.1. Was the admission preventable?

Of the 66 total admissions, 28.7% (19) of admissions were considered to be preventable based on the audit criteria and 7.6% (n=5) were 'possibly' preventable. Fifty-nine percent (n=39) of admissions were not considered to be preventable. In three cases it was not possible to assess this from the notes.

In total 24 admissions were considered to be preventable or possibly preventable. Most admissions (58.5%, n=38) could have been prevented by better access to neuromuscular services, having an emergency plan and surveillance of the patient's condition (Table 16).

Table 16 - Measures which could prevent unplanned or emergency admissions

Intervention/measure	Number of admissions
Access to neuromuscular services	15 (23.1)
Having an emergency plan	15 (23.1)
Surveillance of patient's condition	8 (12.3)
Parent education and reassurance	7 (10.8)
Access to/liaison with other services*	5 (7.7)
Monitoring of repeat admissions for recurrent symptoms	4 (6.2)
Provision of equipment (including orthotics)	3 (4.6)
Having a discharge plan	3 (4.6)
Prevent delay in referral to a neurology service	2 (3.1)
Prevent delay in initial diagnosis	2 (3.1)
Physiotherapy referral/review	1 (1.5)
Total	65

*Other services include community paediatric teams, general paediatric services, feeding/gastrointestinal services.

Unplanned or emergency admissions in children

Of the admissions that were considered to be non-preventable, the main reason for this was because it was the first presentation of symptoms (30.8%, n=12). Other common reasons were because the patient required inpatient care and/or investigations (25.2%, n=10) and because the emergency plan failed (20.5%, n=8) (Table 17).

Table 17 - Reasons why unplanned or emergency admissions were not preventable

Reason for admission	Number of admissions (%)
First presentation of symptoms	12 (30.8)
Required inpatient management	10 (25.6)
Failed emergency plan	8 (20.5)
Acute presentation	6 (15.4)
Followed emergency plan	3 (7.7)
Total	39

6.2.2. Neurology review

During 16 admissions (24.2%) the child had a neurology review and in 43 (65.1%) admissions no neurology review was carried out (although one patient was discussed over the phone). For seven admissions this information was not recorded.

Most of the neurology reviews (68.8%, n=11) carried out for the 16 admissions were by a Neuromuscular Consultant. The remainder 5 reviews were carried out by a Consultant Neurologist.

6.2.3. Length of stay

Length of stay ranged from one day to 190 days with a median of four days. Almost two thirds of admissions of the 66 admissions (n=42, 63.6%) resulted in a length of stay of one week or less. For two admissions length of stay could not be calculated as the date of discharge was not recorded.

Paediatric bed days totalled 787, which was 9% of the total audit bed days despite paediatric admissions making up 11% of the total admissions.

6.2.4. Admission to Intensive Care Unit

Just under a third of paediatric admissions (n=20, 30.3%) included an ICU admission. Length of stay was only available for nine paediatric admissions and ranged from two to 27 days.

6.2.5. Discharge

Five paediatric admissions (7.6%) were considered to have had a delayed discharge. Reasons for delayed discharge were: awaiting suitable discharge destination; awaiting rehabilitation placement; delay in diagnosis; delay in contacting metabolic team regarding the child's feeding regime; delay in repatriation to referring hospital.

The majority of children (72.3%, 48/66) were discharged home, three (4.5%) went back to the referring hospital, eight (12.1%) were transferred to another hospital and two (3.0%) went into intermediate care. Three children died whilst inpatient (4.5%) and for two children this information was not recorded.

7

Discussion

This study has enabled the collection of detailed data on a sample of patients with neuromuscular conditions experiencing unplanned or emergency admissions. This will allow commissioners to better understand the needs of this patient population and identify which interventions may help to reduce these admissions and so optimise the care received and the patient experience.

7.1. Methodology

While this study has collected a dataset on 576 admissions for 395 individual patients it is not clear what proportion of the totality of unplanned or emergency admissions for the neuromuscular population in these regions and over the audit timeframe this sample represents. However given that there are approximately 9,000 patients with a neuromuscular condition in London alone it is likely to be small. It was originally planned that a larger number of hospitals across the four regions would be audited however only 16 participated. Additionally, access to patient notes at Trusts meant that the sample was not evenly distributed across participating Trusts and regions, for example no Trusts in East of England participated.

Anecdotal reports had suggested that the further away from a neuromuscular centre a patient lived, the more fragmented their care. In particular South East Coast SCG had expressed concerns about the appropriateness of emergency care for their patients with neuromuscular conditions as well as the lack of support services such as non-invasive ventilation that these patients sometimes require. However, of the 12 Trusts that participated in the audit, eight were considered to have a specialist neuromuscular service and almost two thirds of admissions (n=376) were to a specialist centre. Additionally of the admissions to a hospital without a specialist service 28 were part of a Trust with a specialist service on another site. Further, only three of the Trusts were outside of London. Therefore it was not possible to map or measure the impact of distance from a specialist centre on care received. Further work at non-specialist hospitals and/or those outside of London could gather data over a broader, more diverse population and enable a more comprehensive picture to be built.

Finally, analyses were restricted to cases where the neuromuscular condition was recorded as a primary or a secondary diagnosis. It is possible that some cases were missed due to the neuromuscular diagnosis being in a lower order diagnostic field

However, while the extent to which the results of this study could be extrapolated is not clear, qualitative themes have been identified which are likely to be applicable to the wider population. Additionally the key aim of the audit was to determine the proportion of admissions in this sample which could have potentially been prevented and this was done.

7.2. Preventable and non-preventable admissions

Over three quarters of individual patients (76.9%) were not known to a neuromuscular service at the first admission for which data were collected and, in total, there were 318 admissions (55%) where the patient was not known to a neuromuscular service. It is not clear what could have been done to identify these patients at an earlier stage. That said given that two thirds of preventable admission resulting from known neuromuscular disease are not known to neuromuscular services, it may be that there is potential to close this gap through better signposting and integration of care pathways. Furthermore, a number of patients in this study presented several times with recurrent symptoms and it would seem that this too could respond well to better surveillance and signposting and integration of care pathways.

The relatively high proportion of admissions among patients with known neuromuscular conditions who are not known to a neuromuscular service may suggest that focussing on increasing engagement with patients already known to specialist centres may not be an optimal strategy.

Discussion

Good communication between health care professionals and with patients is an essential part of care of these patients. In the present study there were a number of cases where it was not possible to assess preventability from the case notes and it was not possible to identify whether a patient had been reviewed by the neurology team. In addition, 16.5% of neuromuscular related admissions may have been prevented if the patient had an emergency or discharge plan, highlighting the importance of discussing the management and care with patients at discharge.

Most (69%) admissions related to a known neuromuscular condition were potentially preventable. This was due to a combination of factors including surveillance of the condition, access to neuromuscular services and through having an emergency plan. Emergency plans, shown to be a key intervention which could potentially prevent unplanned admissions, seemed under provided and underutilised.

For patients who present with new or acute symptoms, diagnostic and referral pathways could potentially be improved by developing links between specialist centres and local hospitals for advice on the identification and management of potential patients with neuromuscular conditions.

7.3. Access to other services

For patients with a pre-existing neuromuscular condition the cohort was fairly evenly split between those whose diagnosis for the admission was linked to their underlying neuromuscular condition (47%) and those for whom it was not (43%). Whilst admissions unrelated to known neuromuscular disease were three times less likely to be preventable (21% vs 63%), nevertheless it is important, especially given that the median age of the audit population was 61, for patients to be able to access other specialist and non-specialist services including cardiology, oncology and care of the older person.

7.4. Delayed discharge

Just under a fifth of admissions were felt to have a delayed discharge and the largest single reason for this was ready access to inpatient investigations and clinical opinion. Better links between specialist centres and local hospitals could again possibly help improve this. Other reasons included issues around accommodation and continuing care packages suggesting the need for improved links with social care. Access to wheelchair and orthotics services was not found to be significant reasons for delayed discharge in this study, although such access was found to be important in preventing admission in patients with known neuromuscular conditions.

Over half of the patients considered to have a delayed discharge also had admissions that were felt to be preventable including one patient who had an inpatient stay of almost a year (340 days). It seems clear that scarce NHS resources need to be used in more effective ways to prevent such high costs to the NHS and also to patients with neuromuscular conditions and their families.

7.5. Conclusion

This study has described the experiences of a sample of patients with a neuromuscular condition and has found that over a third of admissions in this sample (37.5%) were preventable and a further 5% were 'possibly' preventable. This not only places potentially unnecessary stress on patients and their families but also represents a significant opportunity cost to the NHS.

The study has also highlighted measures which could potentially prevent such admissions and commissioners should work with neurology and neuromuscular services to develop integrated referral and management pathways to ensure that all patients with neuromuscular conditions have access to the right care at the right time whether that is in a specialist centre, local hospital or in the community.

8

Recommendations

- 1 Monitoring of known neuromuscular patients and access to neuromuscular services between clinic appointments should be strengthened. This could be co-ordinated in a more formal process by the service, for example by the clinical nurse specialist.
- 2 The specialist neuromuscular centre should co-ordinate care across different sub-specialities (neuromuscular, cardiac and respiratory). Fragmentation of care across different hospitals should be avoided, where possible, to ensure good communication, avoid conflicting advice and provide an integrated care pathway.
- 3 All patients with a known neuromuscular diagnosis should have a documented emergency plan which specifies a clear point of access for emergency care. This may include telephone access for the patient to the specialist neuromuscular centre during times of worsening health.
- 4 Specialist neuromuscular centres should develop links, preferably with outreach, with local hospitals to enable advice, diagnosis and referral to be managed in a timely fashion. Links should also be improved with local social services to ensure a patient's ongoing needs can be met and prevent delays in discharge due to social issues.
- 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:
 - a Documented referral to the neurology team even if the neuromuscular condition is not the prime reason for admission
 - b Emergency plan on discharge

Health professionals should ensure that there is clear documentation of any review of a patient.

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Next Steps

- The findings of this study will be presented to the:
 - All Party Parliamentary Group for Muscular Dystrophy
 - Pan-Specialised Commissioning Group Neuromuscular Working Group to take the recommendations forward
 - British Myology Society Annual Meeting
- This study will be used to inform the development of a neuromuscular service specification and tools to support the commissioning of neuromuscular services by the Neurosciences Clinical Reference Group.

10

References

1. *Muscle Disease: the impact. Incidence and Prevalence of Neuromuscular Conditions in the UK.* Muscular Dystrophy Campaign, January 2010
2. *Access to Specialist Neuromuscular Care: The Walton Report.* All Party Parliamentary Group for Muscular Dystrophy, 2009
3. *Building on the Foundations: Invest to Save. Improving services and reducing costs.* Muscular Dystrophy Campaign, May 2011
4. *NHS Data Model and Dictionary (version 3.0).* Connecting for Health, 2010

Appendix 1: List of Trusts invited to participate

Trust Name
Barking, Havering and Redbridge University Hospitals NHS Trust
* Barts Health NHS Trust
Brighton and Sussex University Hospitals NHS Trust
* Cambridge University Hospitals NHS Foundation Trust
* Great Ormond Street Hospital for Children NHS Foundation Trust
* Guy's and St Thomas' NHS Foundation Trust
Homerton University Hospital NHS Foundation Trust
* Imperial College Healthcare NHS Trust
* King's College Hospital NHS Foundation Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
North West London Hospitals NHS Trust
* Oxford University Hospitals NHS Trust
* Royal Free London NHS Foundation Trust
* University Hospital Southampton NHS Foundation Trust
* University College London Hospitals NHS Foundation Trust
Whipps Cross University Hospital NHS Trust

* Denotes a Trust with a specialist neuromuscular service

Part of Barts Health NHS Trust as of 1st April 2012

Appendix 2: List of associated outreach hospitals

Trust Name	
King's College Hospital	Bromley Hospital
	Princess Royal University Hospital
	William Harvey Hospital
	Queen Elizabeth Hospital
	Queen Marys Hospital
	Darent Valley Hospital
	Tunbridge Wells Hospital
	Kent and Sussex Hospital
	Kent and Canterbury Hospital
	Maidstone Hospital
Evelina Children's Hospital	Lewisham Hospital
	Medway Maritime Hospital
	Kent and Canterbury Hospital
	Maidstone Hospital
Charing Cross Hospital	Chailey Hospital
	Ealing Hospital
	St Mary's Hospital
Royal Free Hospital	Hillingdon Hospital
	Welwyn Garden City Hospital
Addenbrooke's Hospital	West Hertfordshire Hospital
	West Suffolk Hospital
John Radcliffe Hospital	Milton Keynes Hospital
	St Richard's Hospital, Chichester
University College London Hospital	Northwick Park Hospital
	Central Middlesex Hospital
	Homerton University Hospital
	North Middlesex Hospital
Royal London Hospital	Broomfield Hospital
	Basildon Hospital
	Southend Hospital
	Colchester Hospital
	Homerton University Hospital

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