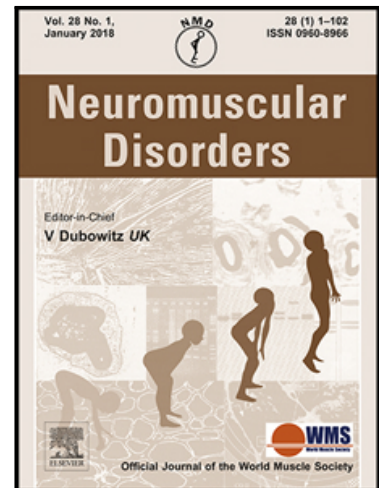


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Improving specialised care for neuromuscular patients reduces the frequency of preventable emergency hospital admissions

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### Highlights

- Emergency admissions are frequent in people with NMD
- Preventing emergency admissions improves quality of life
- Anticipatory care prevents admission
- Quality of life is improved
- Health care costs are reduced

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## Improving specialised care for neuromuscular patients reduces the frequency of preventable emergency hospital admissions

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### Abstract

Two retrospective audits were undertaken across several hospitals to understand the frequency and preventability of emergency admissions in people with neuromuscular disease (NMD). Following audit 1 (A1), a number of preventable themes emerged on the basis of which recommendations were made to improve quality and co-ordination of care and a network approach was developed to improve awareness and education amongst patients and non-expert professionals. Audit 2 (A2) was undertaken to determine the effect of these measures. The central NHS IT database identified emergency NMD admissions. Case notes were reviewed and audited against pre-agreed criteria. A1 included 576 admissions (395 patients) A2 included 361 admissions (314 patients). Preventable admissions (where an NMD was known) accounted for 63% in A1 and 33% in A2, with more patients followed up at a specialized neuromuscular centre in A2. There were fewer re-admissions in A2 (12%) compared with A1 (25%) and lower mortality (A1: 4.5%, A2: 0.3%). A2 showed a significant rise in patients admitted under the care of neuroscience during the acute admission and fewer preventable ITU admissions. These audits demonstrate a significant impact for both patient care and potential for financial savings following the implementation of recommendations made after A1.

\*Percentages expressed in the text have been rounded up or down to the nearest whole number

**Key words:** Neuromuscular Diseases, Emergency Admissions, Public Health, NHS, A&E

**Abbreviations:** ITU: Intensive Therapy Unit; NHS: National Health Service; NMD: Neuromuscular Disease, NMDs: Neuromuscular Diseases, NMCCC: Neuromuscular Complex Care Centre; UCLH: University College London Hospitals, UK: United Kingdom

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## INTRODUCTION

In the UK, it has been estimated that 71,000 people have a neuromuscular disease (NMD) many of which have a progressive course leading to significant disability with multi-system involvement; such patients require life-long specialised multi-disciplinary care. However, several reports indicate that access to specialised neuromuscular services is variable and patient satisfaction for hospital services could be improved [1, 2, 3]. In the United Kingdom in recent years emergency hospital admissions have been rising [4-7] at a substantial cost for commissioners. In 2011 there were estimated to be over 28,000 emergency admissions across the UK relating to people with NMD alone, representing a cost to the National Health Service (NHS) of over £81 million [8]. People with NMD may have many specialists and therapists involved in their care (neurology, respiratory, cardiac, endocrine, gastrointestinal, pain, palliative and therapies) often these specialists are based in different departments and hospitals leading to fragmented care [3]. As a consequence, frequently there is no clear point of access for emergency advice. When admitted to an acute general hospital for an intercurrent illness or injury, NMD patients frequently report exposure to inexperienced staff and a lack of disabled facilities [8]. International published standards of care for Duchenne muscular dystrophy (DMD) [9, 10, 11], Spinal Muscular Atrophy [12, 13] and Myotonic Dystrophy [14] emphasize the importance of anticipatory, pro-active management to prevent cardiac and respiratory complications.

Understanding the frequency and preventability of emergency admissions in NMD may help to shape services and develop policy decisions about the provision of, and access to, specialist neuromuscular services and, in particular, may potentially improve efficiency by reducing the frequency and, thus, cost of emergency admissions [5]. To address this question, in 2011 the NHS specialist commissioners for five regions in the UK funded two cross-sectional retrospective case-note review audits, undertaken 5 years apart, to determine the frequency and reasons for emergency admissions in people with NMD and extent to which these admissions could potentially have been prevented [17]. The findings from the first audit (A1) led to a number of recommendations for service improvement and government funding to develop a partnership network between specialist healthcare providers and a leading charity to improve services, educate and disseminate key information to patients and non-expert professionals (table 1). One consequence of these recommendations was the development of a Neuromuscular complex care centre (NMCCC) at one of the specialist referral centres involved in these audits (the National Hospital for Neurology

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and Neurosurgery) which was purpose built and designed to bring all tertiary subspecialists to the patient (Neurology, cardiac, respiratory, gastrointestinal, neuroanaesthetics, psychology, physiotherapy, palliative care, occupational therapy and speech and language therapy) as a 'one-stop' multi-disciplinary assessment. In 2016, NHS England commissioned a second audit (A2) to determine whether the implementation of these recommendations and partnership network had made any impact on the frequency and preventability of emergency hospital admission in people with NMD within the same NHS regions.

## **METHODS**

### **Audits**

Two cross-sectional case note review audits were conducted across the following National Health Service (NHS) specialised commissioning groups: London, South East Region, Wessex, South East Coast and East of England, in 2011 and in 2017. All of the Hospital Trusts in these regions were invited to take part. The project was registered and approved by the internal review boards for each of the participating organisations. Informed consent was not required, and all data were anonymised; any details that could potentially identify a patient's identity were omitted. A list of emergency admissions in people with NMD occurring within the pre-defined audit period was identified via a central NHS England commissioning database using ICD10 codes (both primary and secondary fields) and was linked to the patients' NHS number and admitting hospital. Information regarding non-NMD emergency admissions was not made available, hence, we were not able to compare data with a non-NMD cohort. At each participating hospital, individual patient case-notes were reviewed by a doctor trained in NMD. Data were entered immediately into a pre-agreed data extraction form, which was developed, piloted and validated prior to the start of the project.

A1 assessed case-notes for emergency admissions directly related to an underlying NMD during the period: 1st January 2009 until 30th June 2011 [17]. A2 assessed case-notes for emergency admissions from 1st January 2014- until 30th June 2016 [18]. Where there were: incomplete medical notes, elective admissions, incorrect coding i.e. absence of a diagnosis of NMD and obstetric admissions data were not included in the audit. Collected data included: primary neuromuscular diagnosis, whether or not the individual was known to a specialised neuromuscular service, reason for admission i.e. non-neuromuscular diagnosis, admission route (emergency room or acute medical

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admission unit), admission characteristics, preventability of admission (scored as: definite, possible or not preventable), the nature of intervention required, duration of admission and whether an emergency plan was documented. For patients who had multiple emergency admissions, demographic information was taken from the first admission notes. Criteria for preventability included: admissions for acute on chronic respiratory failure, chest infections, cardiac failure and/or cardiac arrhythmias, falls resulting in injury such as fractures, immunosuppressant treatment failure (including lack of compliance), myasthenia relapse, other complications e.g. pseudo-obstruction due to constipation and malnutrition. Data were also documented on re-admission following discharge and prolonged admission. Following analysis of the data acquired from A1, key risk factors for preventable unplanned admissions were identified resulting in the recommendations and details of the network/partnership aims (table 1). The same methods and criteria were used for A2 to understand the effect of these recommendations and network/partnership approach on emergency admissions.

## RESULTS

Table 2 summarises the participating hospitals (there were 12 in A1 and 9 in A2) and also outlines the acute attending services involved in emergency NMD admissions. The population demographics were comparable in both audits: 54% men and 45% women (unknown: n=1) in A1, with a median age of 61 years (range 0 to 96); in A2, 55% men and 45% women, with a median age of 55.5 years (range 0 to 94). In A1 there were 576 unplanned admissions in 395 patients, and in A2 there were 361 admissions in 314 patients. Three Trusts who participated in A1 did not participate in A2, the reasons for this are unknown as they did not respond to communication from the audit team, these three hospitals accounted for missing data relating to 28 emergency admissions. The number of readmissions in people with NMDs was 25% in A1 and 12% in A2, figures 1a and 1b demonstrate the number of admissions per individual patient in both audits which ranged from 1-6 in A1 and 1-4 in A2. In A1 86/576 (15%) of NMD acute admissions were admitted under the care of neurosciences compared with 79/361 (77%) in A2. Documented evidence for a Neurology consultant review during an acute admission was identified in 33% (unknown: 8%) of case notes in A1 compared with 82% in A2 (unknown: 5%).

### Specialised Services

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In A1, 64/395 (16%) of patients (unknown: 7%) were previously known to a specialised NMD service compared with 128/361 (35%) of patients (unknown: 13%) in A2. Further analysis performed in A2 showed that hospital stays were shorter for admissions where patients were known to a specialised NMD service (median: 8 days) compared with patients who were not known to a specialised NMD service (median: 15 days).

### **Preventability**

Preventability of admissions is summarised in table 3. Admissions scored as 'preventable' accounted for 216/576 (37%) of all admissions in A1 and 79/361 (22%) in A2. The proportion of preventable admissions for patients with a previous known diagnosis of NMD was shown to have reduced by almost 50% from 143/127 (63%) in A1 to 63/192 (33%) in A2 [18]. In A1 there were 63 admissions to intensive care, 32% of these admissions were considered preventable and only 28% of patients were known to a neuromuscular service. The length of stay ranged from 1-340 days with a median length of stay of 6 days. In A2, there were 64 admissions to intensive care, 11 (17%) of these admissions were considered preventable. In A2 patients who were known to a specialised NMD service had fewer ITU admissions 18/128 (14%) than those who were not known to a specialised service 40/187 (23%). The length of stay for intensive care admission in A2 was 1-102 days, median 9 days.

A1 identified a number of themes which, had they been in place, might have prevented an admission for individual patients including: surveillance of the condition (27%), access to a specialized service (22%), having an emergency care plan (12%), access to or liaison with other services (8%), prevent delay in referral to neurology (6%), provision of equipment including orthotics (7%), prevent delay in initial diagnosis (6%), patient parent education (4%), physiotherapy referral/review (4%), monitoring of repeated admissions (3%) and finally each theme accounting for 1% of preventable admissions or less: access to social services, access to substance abuse services, discharge plan, improved transition [17]. On the basis of these findings, the recommendations for improvement in table 1 were made.

### **Discharge**

Most patients were discharged to home. In-hospital mortality reduced from 4.5% (A1) to 0.3% (A2) (table 4). However, delayed discharges increased from 105/576 (18%) to 91/361 (25%) from A1 to A2, although there was a

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reduction in repeated admissions from A1 to A2 (figure1). There were incomplete data regarding delayed discharge in 64 sets of medical notes assessed in A2. Most common reasons for delayed discharge in A2 were medical complications, multiple factors and access to rehabilitation/intermediated care. Fewer patients died during the second audit period, in A1 there were 26/576 deaths (4.5%) compared with 1/361 (0.3%) in A2.

### **Emergency Care Plans**

There were few documented emergency care plans, 12 in A1 and 5 in A2.

### **Limitations**

We were unable to access data from three hospitals in A2, which accounted for 28 emergency admissions. In A2, 120 elective admissions were filtered by the NHS as 'emergency admissions' based on an incorrect ICD10 code and were excluded from data analysis as they related to elective admissions. Incomplete medical notes may have compromised counting of ITU bed days, delayed discharge analysis and emergency plan documentation.

### **DISCUSSION**

These two retrospective case note review audits (A1 and A2) conducted over a five-year interval aimed to identify the number and reasons for preventable emergency admissions in people with NMD, the full reports of these audits can be accessed on line [17, 18]. It was anticipated that by reducing emergency admissions for this population, significant cost savings could be made and the quality of life for NMD patients improved.

The results of A1 identified risk factors for preventable unplanned admissions which led to a number of recommendations aimed to reduce the frequency of preventable emergency admissions in people with NMD [17]. These recommendations are summarized in table 1 and include improving access to specialized care for NMD patients, better co-ordination of multi-specialty care to reduce fragmentation (thus improve compliance) and provision of an emergency care plan or patient passport, where the patient is the carrier of essential aspects of their hospital record. In addition a partnership network was developed between a charitable organisation; muscular dystrophy UK (MDUK) and NHS providers called 'Bridging The Gap' (funded by NHS England) [19]. The network's main goals were: to improve knowledge and awareness of NMD through education and dissemination of information

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to both patients and non-specialists, by creating neuromuscular networks between specialized centres and peripheral teams, to improve patient access to specialized centres, improve emergency access through emergency care plans and liaison with ambulance services (to prevent delay) and to work with specialized centres to improve care (for example by improving provision of equipment such as cough assist machines and improve therapy provision to prevent falls). Improvement in services was achieved by developing a benchmarking scheme to audit specialized services and award 'Centre of Excellence Status', which was achieved by three of the participating hospitals by A2. In addition, one major tertiary centre developed a Neuromuscular Complex Care Centre (NMCCC) to co-ordinate all multi-disciplinary assessments (neurology, respiratory, cardiac, gastroenterology, physiotherapy, speech therapy, occupational therapy and psychology) around a routine sleep study thus reducing fragmentation of services with better communication between teams and, most importantly, reduced hospital visits for patients, thus improving compliance [16].

A2 demonstrated a positive impact of the strategy outlined in the recommendations for improvement. There was documented evidence that a greater percentage of patients with a known NMD were under regular follow up by a specialized neuromuscular centre. Furthermore, there was a significant reduction in preventable emergency admissions for patients with a known neuromuscular disease. Emergency admissions which could not be prevented included conditions where the first presentation was acute, for example Guillain-Barre syndrome and Myasthenia Gravis. In addition, in A2 there was evidence for better awareness of NMD in acute hospitals since a much greater percentage of patients were admitted under a neurology firm and had a documented review by a consultant neurologist during their acute admission, there was a reduction in preventable ITU admissions and fewer deaths.

Emergency Care Plans were rarely documented in the medical records in either audit. It is unclear as to whether these care plans were available but simply not documented or whether they did not exist. Emergency care plans containing information about the primary condition, standards of care (where they are available) and contact details of professionals involved in that patient's routine care would provide valuable information to non-specialized acute services managing the patient with a rare NMD and are to be recommended.

A2 showed there to be an increase in length of stay as evidenced by an increase in delayed discharges, the cause is unclear. One possible explanation could relate to the observed reduction in readmissions (presumably due

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to premature discharge) between A1 and A 2 and/or perhaps also improved survival of the sickest patients, who might have otherwise died, taking longer to recover.

This study suggests that emergency hospital admissions in NMD can be prevented by specialist neuromuscular input co-ordinating all aspects of care. This is not surprising given that specialized neuromuscular care is usually anticipatory and proactive for example: regular monitoring of respiratory function including sleep studies to anticipate the need for cough assist techniques and night-time non-invasive ventilation, regular cardiac monitoring to prevent life-threatening cardiac arrhythmias and early introduction of ACEI and beta blockers to prevent cardiac failure, monitoring weight and diet to prevent malnutrition may reduce chest infections and regular physiotherapy input with the use of orthotics may prevent falls [9-14]. Reducing preventable emergency admissions have the potential for significant cost savings to health care funders and substantial improvement in the quality of life for NMD patients. Better co-ordination of care and improved communication between specialties should be a goal for all specialized neuromuscular centres.

### **Conclusions and implications**

We have undertaken the largest reported NHS audits of emergency hospital admissions in patients with NMD in England. Our results show significant improvement in the reduction of preventable emergency admissions for people with NMD over a 5 year period. Interventions that have contributed to this improvement include: increased proportion of NMD patients known to specialized neuromuscular centres with co-ordination of multi-disciplinary care by specialized centres, better links and improved education of patients and non-specialist acute teams through a network/partnership approach with charity. Other improvements noted included an increase in patients admitted acutely under a neuroscience service and the review of acutely ill patients by a consultant neurologist, fewer preventable ITU admissions and reduced mortality. Furthermore, there were fewer readmissions to hospital following an acute event. The impact of emergency care plans is not known due to the small number of documented plans seen patient records. It is possible that emergency care plans could improve acute care further.

\*Percentages expressed in the text have been rounded up or down to the nearest whole number

**Authors Contributions:**

RS Scalco: acquisition, analysis and interpretation of data for Audit 2; manuscript draft.

R M Quinlivan: study design, supervision, reviewed data analysis, manuscript writing and critical revision of manuscript.

L Nastasi: data acquisition review of the statistical analysis.

F Jaffer: data acquisition

MG Hanna: study concept, study design, supervision, reviewed data analysis and critical revision of manuscript.

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## Figure Legends

## Figure 1: Number of readmissions

Number of admissions per patient decreased between audit 1 and audit 2

Figure 1a A2 number of admissions per patient

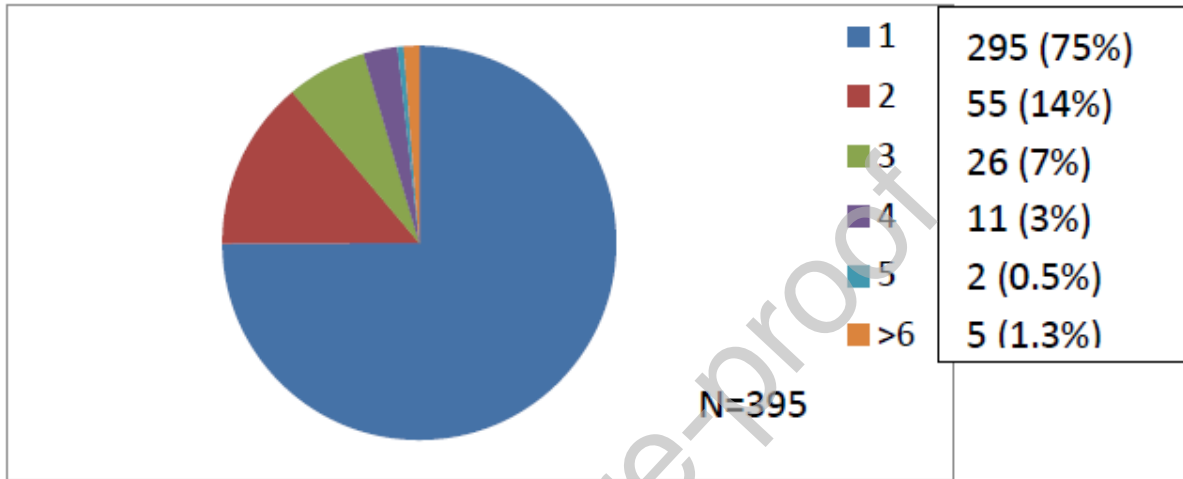
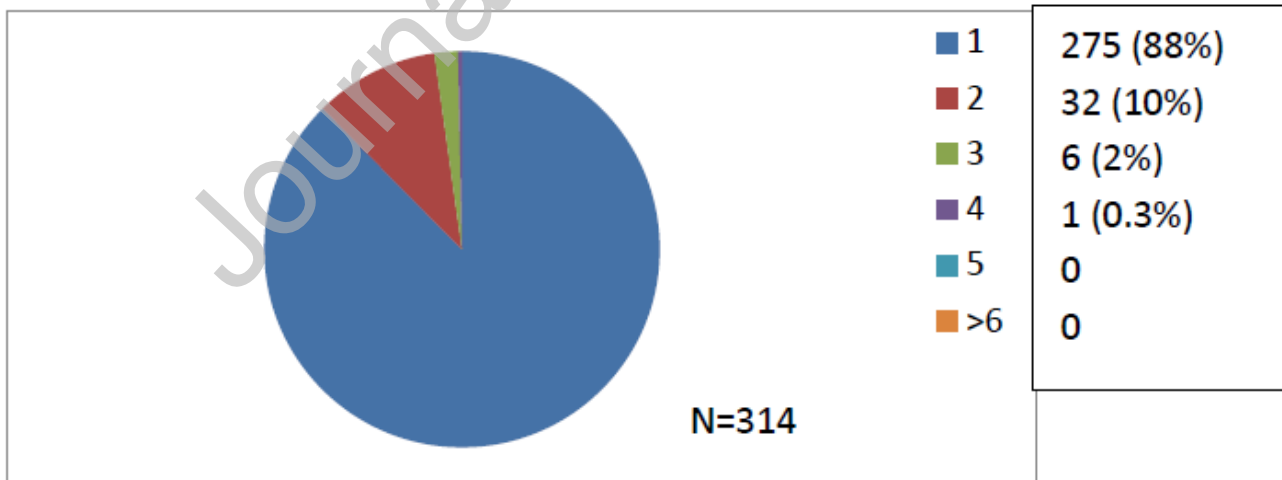


Figure 1b A2 Number of admissions per patient



\*Percentages expressed in the text have been rounded up or down to the nearest whole number

Table 1

**Key recommendations to prevent emergency admissions following A1**

<b>Key Recommendations following A1</b>
<ul style="list-style-type: none"> <li>• Monitoring of known neuromuscular patients and access to neuromuscular services between clinic appointments should be strengthened</li> <li>• The specialist neuromuscular centre should coordinate care across different sub-specialties, avoiding fragmentation of care across different hospitals</li> <li>• All patients with a known neuromuscular diagnosis should have a documented emergency plan.</li> <li>• Specialist neuromuscular centres should develop links with local hospitals to enable advice, diagnosis and referral to be managed in a timely fashion</li> <li>• 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</li> <li>• 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</li> <li>• 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</li> </ul>
<b>Partnership/ network approach (health care providers and charity)</b>
<ul style="list-style-type: none"> <li>• A Clinical Network for London and South East Coast Neuromuscular services was established to engage patients in services, upskill local teams and improve quality of care</li> <li>• Development of neuromuscular condition alert cards and a template for emergency care plans were produced</li> <li>• An online map of all neuromuscular clinics and specialist services was created to signpost patients to their nearest specialised service</li> <li>• Development of an ambulance flagging system for people with neuromuscular conditions in London</li> <li>• Provisional of peer-to-peer support network through a patient organisation: Muscular Dystrophy UK</li> <li>• The creation of the best practice commissioning policy for cough assist machines</li> <li>• Improved education and awareness for GPs and physiotherapists in the care of people with neuromuscular conditions through online training modules</li> <li>• Eleven new NHS-funded neuromuscular roles were created and two existing roles were secured in the audit region</li> <li>• Benchmarking and auditing specialized neuromuscular services to create 'centres of excellence'</li> <li>• Neuromuscular Complex Care Centre (NMCCC) was opened at The National Hospital for Neurology and Neurosurgery</li> </ul>

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Table 2

Participating hospitals, number and distribution of admissions and attending service under whose care the patients were admitted

Hospital	A1 Admissions (Patients)	A2 Admissions (Patients)	Attending Service	A1	A2
Barts Health NHS Trust	50	50 (40)		n (%)	n (%)
Brighton and Sussex University Hospitals	66	34 (31)	Neurosciences	86 (15)	278 (77)
Barking, Havering and Redbridge University Hospitals	32	X**	Paediatrics	63 (11)	43 (12)
The North West London Hospitals NHS Trust	58	X**	General Medicine	306 (53)	12 (3.5)
Guy's and St Thomas' NHS Foundation Trust* (Evelina Children's)	6	0 (0)	Rheumatology	8 (1.5)	7 (2)
Great Ormond Street Hospital for Children*	7	9 (7)	ITU	9 (2)	5 (1.5)
Homerton University Hospital	16	X**	Respiratory medicine	5 (1)	2 (0.5)
Imperial College Healthcare NHS Trust* (Charing Cross and Hammersmith)	46	20 (20)	Thoracic Medicine	-	2 (0.5)
Oxford University Hospitals NHS Trust* (John Radcliffe)	103	73 (59)	A&E	13 (2.5)	1 (0.5)
University College London Hospitals NHS Foundation Trust*	37	25 (25)	Gastroenterology	3 (0.5)	1 (0.5)
Royal Free Hospital*	45	47 (36)	Medicine of Elderly	5 (1.0)	1 (0.5)
University Hospital Southampton*	110	103 (96)	Haematology	2 (0.3)	1 (0.5)
<b>Total</b>	<b>576 (395)</b>	<b>361 (314)</b>	Cardiology	6 (1.0)	1 (0.5)
* denotes hospitals with a specialist neuromuscular service ** denotes hospitals who did not respond to the request to participate in audit 2 (% have been rounded to nearest 0.5%)			Surgery	32 (6)	1 (0.5)
			Unknown	5 (1)	6 (2)
			Others	33 (6)	-
			<b>Total</b>	<b>576</b>	<b>361</b>

\*Percentages expressed in the text have been rounded up or down to the nearest whole number

Table 3

## Preventability of admission

Preventability n = admissions (%)	A1 All patients	A2 All patients	A1 Previously known NMD	A2 Previously known NMD	A1 Under 16s	A2 Under 16s	A1 ITU admissions	A2 ITU admissions
No	327 (57%)	204 (56.5%)	67 (29.5%)	71 (37%)	39 (59%)	23 (50%)	34 (54%)	38 (59.5%)
Yes	216 (37.5%)	79 (22%)	143 (63%)	63 (33%)	19 (29%)	12 (26%)	20 (32%)	11 (17%)
Possibly	28 (5%)	70 (19.5%)	13 (6%)	51 (26.6%)	5 (8%)	9 (20%)	6 (9.5%)	13 (20%)
Uncertain	5 (0.9%)	8 (2%)	4 (2%)	7 (4%)	3 (4.5%)	2 (4.5%)	3 (5%)	2 (3%)
<b>Total</b>	<b>576</b>	<b>361</b>	<b>227</b>	<b>192</b>	<b>66</b>	<b>46</b>	<b>63</b>	<b>64</b>

Number of admissions considered not preventable i.e. acute presentation of NMD such as Guillain-Barre Syndrome vs those considered preventable or possibly preventable.

(% have been rounded up or down to nearest 0.5%)

\*Percentages expressed in the text have been rounded up or down to the nearest whole number

**Table 4****Patient discharge location and mortality**

<b>Discharge Location</b>	<b>A1 n (%)</b>	<b>A2 n (%)</b>
Home	444 (77)	250 (69.5)
Unclear or not recorded	12 (2)	41 (11.5)
Intermediate care	12 (2)	31 (9)
Transfer back to referring hospital	19 (3.5)	14 (4)
Transferred to another hospital	49 (8.5)	11 (3)
Nursing care	9 (1.5)	10 (3)
Back to residential care	5 (1)	3 (1)
Deceased	26 (4.5)	1 (0.5)
<b>Total (Admissions)</b>	<b>576</b>	<b>361</b>

(NB % have been rounded up to nearest 0.5%)