

# AUDIT OF DISCHARGE OF CHILDREN ON LONG-TERM VENTILATION

March 2015

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# **EXECUTIVE SUMMARY**

#### Background

In 2013, the Health and Social Care Board (HSCB) produced a draft document 'Discharge Pathway for Children with very Complex Health Needs' outlining standards for various stages along the pathway. The Discharge Pathway highlighted eight stages outlining steps and timelines for key interventions to support an appropriate discharge for children returning home requiring long term ventilation (LTV). LTV is defined as the need for respiratory support delivered either by a tracheostomy and invasive mechanical ventilation (IMV) or delivered with a fitted face mask and non-invasive ventilation (NIV).

#### Aim

This audit was conducted to measure the extent to which the standards were being met retrospectively to provide a baseline for assessing future performance; to provide information that may require revision to the Discharge Pathway for children dependent on LTV; and provide direction for optimising the management of available resources and hospital discharge for this unique group of children.

#### Process

Using an agreed audit proforma, data were collected from the clinical records maintained by discharge coordinator and the medical records within the Royal Belfast Hospital for Sick Children (RBHSC). Records between 1<sup>st</sup> September 1997 and to 31<sup>st</sup> August 2013 were audited. *Within the records, there was an absence of documentation relating to dates and times in the discharge process; furthermore, hospital and community records (involving various disciplines) were kept separately, hence findings presented in this audit may under estimate the targets.* 

#### Main findings

During the audit period, records showed 48 children living at home and requiring LTV. Approximately two thirds were admitted and discharged from the RBHSC, and the others commenced LTV as outpatients or a District General Hospital (DGH). The majority of children (60%) require NIV only and 40% require IMV which is more resource intensive in terms of equipment and carers. A breakdown of other characteristics can be found on pages 10-15.

The records from 38 children admitted and discharged from the RBHSC provide information on timelines in the discharge process. The major steps are referral to the discharge coordinator; the initial meetings; obtaining a home care package; parent training; carer recruitment and training.

Referral to the discharge coordinator within two weeks of admission is generally the signal to begin the discharge process: this target was not met. Time to referral was on average three weeks for children requiring NIV and 20 weeks for children requiring IMV.

The set timescale for the initial multidisciplinary team (MDT) discharge meeting and following this the meeting with parents is four weeks: the targets were not met. The average time for the MDT meeting was 25 weeks for children requiring IMV, and between four and twelve weeks for children requiring more or less than eight hours of NIV.

A home care package is generally required to support these children. The set timescales for request and final agreement are eight and twelve weeks: these targets were not met. For children requiring IMV, the time for a request and final agreement were on average 28 and 46 weeks.

Parental training to care for their child is set to begin at 12 weeks: approximately half of the records for children requiring IMV and NIV showed that this target was achieved. Parental competence set at a target of 16 weeks was achieved by very few parents of children requiring IMV with an average time of 43 weeks.

The set timelines for carer recruitment and training competence are 13 and 20 weeks respectively. No cases met these targets. The average timelines in the records available for children requiring IMV were 37.6 weeks for recruitment and 73 weeks for competent training.

The set target for discharge home is 20 weeks: this was achieved in the majority of records for children requiring NIV, although only achieved by 33% of children requiring IMV where the average was 31 weeks (with a range of five weeks to three years).

The major barriers delaying discharge mainly concerned the health service rather than factors associated with the child. These were recruitment and training of carers; arranging transition to DGHs; community assessment delays; equipment and funding delays.

#### Audit summary table

The table on the next page summarises the audit results. The first two columns show the steps and recommended times outlined in the Public Health Agency (PHA) and HSCB (2013) Draft Discharge Pathway for Children with very Complex Health Needs. Column three shows the targets set by the research team at RBHSC. The three columns on the right show the targets achieved and these are split into three categories to reflect the complexity of the child's respiratory support needs: IMV; NIV for more than eight hours/day; NIV for less than eight hours/day.

# AUDIT SUMMARY TABLE

Steps in Discharge process	Set standard	% target	% of recorded standard times	data meeting t cale	he target
	timescale (Weeks)	set	IMV - Tracheostomy (Invasive	NIV (Non-inva ventilation)	asive
			mechanical ventilation)	> 8 hrs duration	≤ 8 hrs duration
Inform Discharge Co-ordinator	2	100	0	0	17
Notify child's home trust	2	100	0	0	100
Multidisciplinary discharge meeting	4	100	0	50	17
Estimated discharge date agreed	4	100	9	33	0
Plan agreed	4	100	0	-	0
Equipment list drawn up	4	90	0	0	-
Meeting with parents	4	100	0	50	0
Risk assessment of home environment	4	100	0	-	0
Emergency services notified	8	100	0	-	-
Readmission plan	8	100	0	0	0
Medical assessments complete	8	100	10*	47	53
Care package requested	8	90	0	-	0
Care package agreed	12	100	0	-	-
Parent training started	12	100	45	33	50
Carer recruitment started	13	100	0	-	-
Equipment order placed	14	90	0	100	50
Equipment service contract agreed	14	90	0	-	-
Trial discharge to home	16	100	11	100	50
Parents competent	16	100	20	100	33
Carers interviews	16	100	33	-	-
Carers in post	18	90	0	-	0
Carers competent	20	100	0	-	0
Medical summary completed	20	100	14	0	100
Contact with parents post- discharge	1	100	14	0	0
Home discharge (defined from initial discharge meeting)	20	90	33	100	80

\*no. of recorded assessments across nine disciplines meeting the set target / no. of recorded assessments across nine disciplines (\_)represents no records

#### INTRODUCTION

Discharge from hospital is a lengthy and complicated process for a small, unique group of children dependent on long-term ventilation (LTV)<sup>1, 2</sup>. It can be delayed for multiple reasons associated with the medical condition, patient needs, family circumstances and healthcare resources. An audit is required to detail the time of events during the discharge process, to identify potential obstacles to home discharge and to clarify the characteristics of children discharged with LTV support in Northern Ireland (NI). It is anticipated this audit will direct improvements in the discharge for children on LTV within NI to achieve a timely, successful transition home.

#### BACKGROUND

An increasing number of children are surviving chronic illnesses because of the advanced medical technologies used in neonatal and paediatric intensive care<sup>5</sup>. The most common conditions requiring long-term assisted ventilation are neuromuscular, airway/pulmonary abnormalities, abnormalities in control of breathing (e.g. congenital central hypoventilation) and spinal cord injury<sup>3, 4</sup>. Many children with these conditions are dependent on LTV and without it will die<sup>6, 7</sup>. A recent United Kingdom (UK) census found that the number of children receiving LTV support increased six times over the last decade<sup>8</sup>. Home ventilation is a feasible and successful option for medically stable children dependent on LTV due to improved home-use equipment<sup>5, 9</sup>. It extends life without compromising quality and has considerable psychosocial and developmental benefits for the patient<sup>3</sup>. To aid a smooth and swift transition from hospital to home, the UK Working Party on Paediatric Long-Term Ventilation produced core guidelines for discharge home of children on long-term assisted ventilation<sup>3</sup>. Despite adoption of these guidelines<sup>10</sup> and attempts to apply care pathways, discharge from hospital to home still experiences long delays. As a result children, who are medically stable, are kept on hospital wards longer than necessary during the transition process<sup>4</sup>. Some have spent a maximum of four years waiting to return home<sup>11, 12</sup>. Children on tracheostomy ventilation wait on average 9.6 months for hospital discharge home in the UK<sup>4, 11</sup>. At any time, there are approximately five children dependent on long-term ventilation waiting to be discharged from the Royal Belfast Hospital for Sick Children (RBHSC).

There are high costs (approx. £2,000 per day) associated with delayed discharge home; quality of life for children and their families, finance, health care resources and beds (approx. 12%) are blocked during the transition process within the hospital trusts<sup>13-16</sup>. Hospitals are not an appropriate long-term environment for children. The more time spent in hospital waiting for discharge means more time lost with family and friends at home. The process is drawn out by meeting the varying needs of each child; complications of underlying disease, family

circumstances, social care, ventilation equipment and medical support. These require the provision of appropriate funding, qualified carers, parent training, continuous re-assessment and respite care<sup>17</sup>. Successful discharge requires an extensive assessment of the patient's needs, meticulous planning and coordination, good communication and working relationship with all involved.

This audit is concerned with a special group of children who are medically stable but require LTV to survive. In NI the decision to discharge a child on LTV to home, a district general hospital (DGH) or hospice is taken at the paediatric intensive care unit (PICU) located within the RBHSC.

#### AIM

This audit of the discharge pathway and the time period taken to discharge medically stable children dependent on LTV was conducted to measure the extent to which the standards were being met retrospectively to provide a baseline for assessing future performance; to provide information that may require revision to the Discharge Pathway for children dependent on LTV; and provide direction for optimising the management of available resources and hospital discharge for this unique group of children. This will ultimately benefit children and their families, remove stress caused by the delays in discharge and provide a better quality of life for the children<sup>18</sup>.

#### OBJECTIVES

- 1) To ascertain the characteristics of children dependent on LTV discharged home during the 16 year audit period from RBHSC and other DGH or area hospitals (AH).
- 2) To measure the average time for hospital discharge to home during the 16 year audit period from the RBHSC.
- 3) To determine barriers that delay discharge and impact on discharge time scales.
- 4) To assess the discharge pathway applied in NI against the standard recommended guidelines.

#### **STANDARDS**

A focused set of standards (Appendix 1) was agreed by the Audit Steering Group based on the PHA and HSCB (2013) Draft Discharge Pathway for Children with very Complex Health Needs.

This document is subsequently based on the nationally applied standards from:

- 1. Jardine E, Wallis C. (1998) Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom. Thorax 53; 762-767.
- 2. DHSSPS (2009) Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs.

 Noyes J, Lewis. (2005) Care pathway for the discharge and support of children requiring long term ventilation in the community. Department of Health. National Service Framework for Children, Young People and Maternity Services.

#### PROJECT STEERING GROUP

The project Steering Group for the audit represented Consultant Respiratory Paediatricians from the BHSCT, Respiratory and Neuromuscular Support Nurses BHSCT, Regional Trust Discharge Liaison Nurses, and a Senior Lecturer in Critical Care Queen's University Belfast.

#### METHODOLOGY

This audit collected data retrospectively from clinical records of children identified as being on LTV who have been discharged from the RBHSC during the audit timescale.

Sample

- Children requiring LTV living in NI and who were discharged from the RBHSC.
- Audit time scale: 1<sup>st</sup> Sept 1997 to 31<sup>st</sup> Aug 2013.
- Discharge Liaison Nurse patient case notes and medical notes were included to inform the audit.

Audit tool

- Audit proforma (Appendix 2).
- Pilot was carried out with data collector, Discharge Liaison Nurse and Consultant Respiratory Paediatrician in the RBHSC

Data collection

- Data collector was supported by the Discharge Liaison Nurse.
- Data collected May 2014 to August 2014 using the agreed audit proforma.

Data analysis

- The nominated data collector carried out initial analysis and prepared a draft report.
- Staff were consulted for clarification on data queries.
- Members of the Steering Group reviewed the audit report, constructed a list of recommendations and agreed an action plan.

The report is structured and presented in sections that address the objectives of the audit.

## **Report Findings**

Objective 1. To ascertain the characteristics of children dependent on long-term ventilation discharged home during the 16 year audit period from RBHSC & other DGH.

Forty-eight children on LTV were identified living in NI and were children at the RBHSC during the audit period.

Number of children n=47	Status						
38	admitted to and discharged from the						
	RBHSC						
9	commenced LVT as out-patients						
1*	commenced LTV at a DGH hospital						

\*discharge medical notes were not available for this child at the RBHSC.

#### The following characteristics are based on 47 children receiving LTV.

#### Sex and Age

Of children dependent on LTV living in NI 57% (27/47) are male and 43% (20/47) are female. The median age was eight years (IQR 5-15.5 years, range 1-21 years). The breakdown of numbers within various age categories is shown in Figure 1.



#### Figure 1. The number and current age of children requiring LTV in NI (Table A1, Appendix 4)

# Diagnosis

The clinical diagnoses of the children are presented in Table 1. The largest group (30%, 14/47) consists of a number of 'other syndromes', followed by other neuromuscular (15%, 7/47) and abnormalities of the trachea (9%, 4/47). Figure 2 shows the co-morbidities of children requiring LTV.

Diagnosis	No.	of	children	% children
	(n=47	)		
DMD	3			6
SMA1	1			2
SMA2	3			6
central core myopathy	5			11
other neuromuscular	7			15
tracheal abnormalities	4			9
bronchial abnormalities	1			2
abnormalities in control of breathing	2			4
spinal cord injury	4			9
chronic lung disease	3			6
Other e.g. Golden Har syndrome, Kabuki syndrome,	14			30
Spina bifida				

Table 1. The number and percentage of children with certain diagnosis dependent on LTV

Key: DMD, Duchenne Muscular Dystrophy; SMA1 spinal muscular atrophy TYPE 1 (gene *SMN1*); SMA2 spinal muscular atrophy TYPE 2 (gene *SMN2*).



Figure 2. The comorbidities of children requiring LTV recorded in medical notes (n=26/47)

#### **Respiratory Support**

Respiratory support is provided either invasively through a tracheostomy for 40% (19/47) of children; or non-invasively via a face-mask for 60% (28/47). The current median age of children with a tracheostomy is six years (IQR 2.5-6 years, range 2-18 years) and 42% (8/19) are younger than five years (Figure 3). In ten cases the tracheostomy was inserted in the child's first year of life (median age 3.6 weeks, IQR 1.2-5.7 weeks, range 0.3-55.3 weeks).

The current median age of children requiring non-invasive ventilation (NIV) is 10 years (IQR 6-10, range 1-21 years). There is a greater proportion of children 43% (12/28) that are 5 - 10 years requiring NIV than invasive mechanical ventilation (IMV) through a tracheostomy (Figure 3).



Figure 3. The number and age group of the 47 children requiring IMV and NIV

The interfaces used for delivering NIV were recorded in the medical and discharge notes of 20 cases; data were not found in eight cases. Interfaces used were the full face mask (70%, 14/20), the nasal mask (25%, 5/20) and one child used a face mask during the day and a nasal mask at night. The type of NIV interface used is not age-related (Figure 4).



Figure 4. Type of NIV interface and child's age (n=20 recorded cases)

Ventilator modes included Continuous Positive Airway Pressure (CPAP) and Bilevel Positive Airway Pressure (BiPAP). In 45 cases (date were unavailable for two cases), the age range of children using one or more of these modes is shown in Figure 5. In 43 recorded cases (four cases were not recorded), the mode of respiratory support most frequently used was BiPAP and this was used by 74% requiring IMV (14/19) and 67% requiring NIV (16/24) (Figure 6).



Figure 5. Modes of respiratory support according to age (n=45 recorded cases).



Figure 6. Modes of respiratory support for children requiring NIV and IMV (43 recorded cases).

Data were collected on the duration of respiratory support required by the child on discharge home. Of 44 cases were dates were available, 36% (16/44) required night-time support only, 5% (2/44) for less than six hours per day, 11% (5/44) for less than six hours with additional night-time use, and 48% (21/44) for more than 18 hours per day (Figure 7). Figure 8 shows this information according to the age group of the child.



Figure 7. The percentage of duration periods (hours) for respiratory support (n=44 recorded cases)



Figure 8. Children's age group and duration of respiratory support required on discharge (n=44 recorded cases)

The percentage of oxygen required reflects the severity of the child's respiratory condition. Room air contains 21% of oxygen. Oxygen requirements for discharge home were recorded in 21% (10/47) of case notes and 50% of children required a moderate level of between 28-33% oxygen (Figure 9). For children requiring higher oxygen requirements delivered by IMV, 17% (8/47) were discharged to home with an adapted buggy to carry the oxygen cylinders.



Figure 9. Distribution of oxygen requirements for children on discharge home (n=47 recorded cases)

For clarity of further reporting in this audit, we present the durations of respiratory support required in three groupings; IMV (24 hours/day), > 8 hours and NIV for  $\leq$  8 hours.

# Objective 2. To measure the average time for hospital discharge to home during the 16 year audit period from RBHSC.

The following data relate to the process of hospital discharge to home. We audited the medical and discharge notes of 38 children who were discharged from the RBHSC.

Based on the current draft Discharge Pathway, the target time to discharge a child requiring LTV from RBHSC is 16 weeks (with a range of 12-20 weeks as an acceptable timescale) from the initial multidisciplinary discharge meeting.

The date of the initial multidisciplinary discharge meeting was the start point for measurement of time to discharge from RBHSC and was available in 53% (20/38) medical and discharge notes. Dates for this initial meeting were not always recorded in minutes of the meetings, summary letters or patient notes. Dates of discharge home from RBHSC were available in 90% (34/38) of the medical and discharge notes with the other 10% being illegible on carbon copy paper, the date for a subsequent re-admission, or not recorded.

Over the 16 year audit period, the median time to discharge from the initial multidisciplinary discharge meeting was 19.4 weeks (IQR 7.4-43.8, range 1.1-159.3 weeks) in 47% (18/38) of available records. When measured from hospital admission, the time to discharge was a median of 21.0 weeks (IQR 4.7-55.2, range 0.6-180.8 weeks) in 82% (31/38) of available records (Figure 10).



Figure 10. Median (IQR) time to discharge for all children with LTV from RBHSC.

Although the median time to discharge, measured from the initial discharge meeting, gradually increased over the last decade, the maximum time to discharge has been reduced by 1.82 years (95 weeks). This is shown in Figure 11 in the box and whiskers chart. The whiskers show the maximum and minimum time to discharge (weeks) above and below the IQR box and central median line. From the initial discharge meeting, 56% (10/18) of children were discharged within six months and 17% (3/18) required an extended time period in hospital ranging from 1 - 4 years. Of these children, 67% (2/3) had a tracheostomy.



Figure 11 Median, IQR, and range for time to discharge home over the past 15 years

Depending on respiratory support requirements the time to discharge home from the initial discharge meeting is presented in Table 2. For children requiring NIV >8hrs, the child was discharged home before the Home Care package was finalised.

Table 2. Time to discharge home for recorded cases requiring IMV, NIV > 8hrs NIV  $\leq$ 8hrs respiratory support [dash = no cases]

Discharge home	Respiratory	% (n)	Median	IQR	Range (weeks)
(measured from	support	records	time	(weeks)	
initial discharge			(weeks)		
meeting)	IMV (n=19)	63 (12)	31.3	17.5-47.6	5.1-159.2
	NIV >8hrs	13 (1)	13.3	-	-
	(n=8)				
	NIV ≤8hrs	45(5)	3.6	1.6-8.9	1.1-87.7
	(n=11)				

# Objective 3. To determine barriers that delay discharge and impact on discharge time scales.

Barriers to discharge home were recorded in the notes for 68% (26/38) of children and the frequency with which these were noted is outlined in Table 3. For children requiring IMV, the most frequent barrier to getting home was ensuring an adequate number of trained carers. In two cases, factors leading up to this included partially approved Home Care Packages and suboptimal communication between the hospital and community. Carer recruitment for a third child requiring IMV case was delayed because carers were unable to start until they could be replaced at their existing posts.

Barriers	IMV	NIV > 8hrs	NIV ≤ 8 hrs
	(n=16)	(n=2 )	(n=8 )
	%	%	%
Parental factors e.g. missing appointment, concerned, sick	13	-	50
Transfer to DGH e.g. denied, do not have adequate staff,	19	-	-
transfer delayed			
Carers e.g. recruitment, training, holiday or week-end	31	-	25
cover			
Funding e.g. change in how high cost cases are funded,	6	50	25
rejections			
Housing issues	13	-	-
Patient repeated infections	19		
Community e.g. assessment delays	19	-	-
Equipment e.g. waiting for provision	6	50	-
Patient requiring a clinical intervention	6		-

Table 3. Frequency of a range of barriers delaying discharge to home [dash = no cases]

Objective 4. To assess the discharge pathway applied in Northern Ireland against the RBHSC standard recommended guidelines (appendix 1).

#### **Discharge Pathway steps and timelines**

The recommended Discharge Pathway outlines timescales at stages starting when a patient requiring LTV support is admitted to the regional centre (RBHSC). The timescales were measured from RBHSC admission for 38 children placed on and subsequently discharged with respiratory support.

# STAGE 1: events following admission to RBHSC

Table 4 outlines three key steps in this stage and the time taken to reach those steps.

Discharge step	% (n) patient	Median length	IQR 25-75%	Range	
	notes with date	of time (weeks)	(weeks)	(weeks)	
	(n/38)				
Tracheostomy	29 (11)	3.6	1.2-5.7	0.29-55.3	
Transfer from PICU to	45 (17)	5.4	2.3-27.1	0.1-91.8	
ward					
Decision to discharge <sup>a</sup>	53 (20)	6.5	4.2-23.8	0.3-66.4	

Table 4. Timescale (median time, IQR & range in weeks) for events after admission to RBHSC

<sup>a</sup>This is the point when the planning process for LTV support was commenced, even if the child was not medically fit for discharge.

# STAGE 2: commences within 2 weeks from admission to RBHSC

These steps should normally occur within the two week period following admission. While they frequently occur around the three week period for children requiring NIV, they are delayed for the more complex cases of children that go on to require a tracheostomy and IMV.

Table 5. Timescale (median time, IQR & range in weeks) for steps in the standards based on the draft Discharge Pathway adopted in RBHSC [dash = no cases]

Discharge step	Respiratory	% (n) patient	Median (weeks)	IQR 25-	Range
	support (n/38)	records		75%	(weeks)
				(weeks)	
Referred to	IMV (19)	42 (8)	19.9	5.8-27.5	2.6-55.3
discharge co-	> 8hrs (8)	25 (2)	3.1	2.9-3.4	2.6-3.7
ordinator	≤ 8hrs (11)	55 (6)	3.7	2.3-26.7	1.1-48.9
Contact with home	IMV (19)	11 (2)	26.6	23.6-31.2	22.2-55.3
Trust <sup>b</sup>	> 8hrs (8)	25 (2)	4.3	4.0-4.6	3.7-4.9
	≤ 8hrs (11)	9 (1)	1.1	-	-

<sup>b</sup>Health Visitor, Social Worker and Education are discussed later

We explored whether the time from admission to time to contact the discharge coordinator had changed over the years. We found the average time increased from a median of 3.7 weeks (IQR 2.28-27.92, range 0-48.72) in 2006 to 2010, to 4.99 weeks (IQR 3.27-17.53, range 1.14-55.13) in 2010 to 2014. From 2010, 19% of dates for case referrals to the discharge coordinator were recorded compared with 15% between 2006 and 2010 (Figure 12).



Figure 12. Timescale (Median, IQR, range) of initial contact of discharge co-ordinator from hospital admission

#### Contact with local General Practitioner (GP), health visitor and social worker

The time taken to contact community healthcare staff is shown in Table 6. A limitation of this audit is that the data are taken from records in the discharge coordinator notes in the RBHSC only. The Home Trust maintains its own records.

#### GP contact

In the medical or discharge coordinator notes, records show that GPs were informed of discharge from RBHSC for 58% (22/38) of children. In 26% (10/38) of cases, the patient's GP was involved in discharge arrangements and informed of community care provision. Not informing the patient's GP or health visitor resulted in two complaints (5%, 2/38) from GPs who felt their practice was either not adequately informed or trained to support the family; and in one of these cases the child required IMV.

#### Social worker

Two weeks after hospital admission, the hospital social work manager should be informed of children expected to remain for a period of at least three months. However children's social care notes are not copied to medical records or discharge coordinator files hence they could not be included in this audit. Hospital social workers were present at multi-disciplinary meetings and

hence had early knowledge of the patient. Dated communications with community social workers were made at a median of 44 weeks (IQR 30.2-49.7 weeks, range 3.7-229.7 weeks) *in 24% (9/38) recorded cases.* 

Community	Respiratory	% (n) of	Time from admission (weeks)					Time from admission (weeks)	s)
Contact	support	records	Median	IQR	Range				
GP	IMV (19)	63 (12)	41.4	17.4-57.5	0.4-92.3				
	NIV >8hrs (8)	50 (4)	5.6	4.1-16.8	2.0-48.0				
	NIV ≤8hrs (11)	55 (6)	18.7	6.3-46.2	2.1-57.0				
Health Visitor	IMV (19)	32 (6)	28.9	20.7-49.3	1.1-62.2				
	NIV >8hrs (8)	50 (4)	22.1	4.6-86.9	3.7-229.7				
	NIV ≤8hrs (11)	27 (3)	12.6	8.2-36.5	3.9-60.3				
Social Worker	IMV (19)	32 (6)	37.2	30.2-45.0	15.0-57.3				
	NIV >8hrs (8)	25 (2)	116.7	60.2-173.2	3.7-229.7				
	NIV ≤8hrs (11)	9 (1)	49.7	-	-				
Education	IMV (19)	5 (1)	23.0	-	-				
	NIV >8hrs (8)	25 (2)	90.7	47.2-134.2	3.7-177.7				
	NIV ≤8hrs (11)	18 (2)	59.1	54.6-63.6	50.2-68.0				

Table 6. Time to first contact with Home Trust, local GP, health visitor and community social worker [dash = no cases]

#### The discharge destination

Stage 2 of the pathway indicates that two weeks after admission to RBHSC consideration would be given to deciding the most appropriate discharge destination. Figure 13 shows the discharge destinations recorded in the notes of 38 children. The majority of children were discharged directly to home from RBHSC. A step-down to a DGH hospital, *recorded in 8% (3/38) of cases*, was denied or delayed because nursing arrangements were not appropriate and resources were unavailable at that time to deal with the child's clinical need.



Figure 13. The number of children requiring LTV and their discharge destinations (n=38 recorded cases)

# STAGE 3 (The times below are likely a misrepresentation as many dates were not recorded in notes): timescale 2 - 4 weeks from admission to RBHSC

The following steps are generally taken within Stage 3 between 2 - 4 weeks after admission, but this rarely occurred indicating that the timescale requires modification.

Table 7.	Stage	3 timescales	(median	time,	IQR	&	range	in	weeks)	for	steps	in	the	Discharge
Pathway	. [dash :	= no cases]												

Discharge step	Respiratory % (n)		Median	IQR 25-75%	Range	
	Support	recorded	(weeks)			
		dates				
Multidisciplinary	IMV (19)	63 (12)	24.5	18.5-32.2	8.1-66.0	
meeting <sup>c</sup>	NIV >8hrs (8)	25 (2)	3.7	3.1-4.4	2.4-5.0	
	NIV ≤8hrs (11)	55 (6)	11.7	6.6-31.7	3.6-50.3	
Proposed discharge	IMV (19)	28 (11)	32.5	27.3-70.8	22.2-55.3	
date	NIV >8hrs (8)	38 (3)	15.6	9.1-77.6	2.6-139.7	
	NIV ≤8hrs (11)	9 (1)	50.7	-	-	
Meeting with parents	IMV (19)	37 (7)	30.2	14.1-43.0	4.0-62.0	
	NIV >8hrs (8)	25 (2)	3.2	2.8-3.6	2.4-4.0	
	NIV ≤8hrs (11)	9 (1)	50.3	-	-	

Written discharge plan <sup>d</sup>	IMV (19)	26 (5)	29.0	20.0-30.2	7.1-77.5
	NIV >8hrs (8)	0 (0)	-	-	-
	NIV ≤8hrs (11)	18 (2)	72.0	41.1-103.0	10.1-133.9
	IMV (19)	0 (0)	-	-	-
Education <sup>e</sup>	NIV >8hrs (8)	13(1)	4.9	-	-
	NIV ≤8hrs (11)	9(1)	34.9	-	-
Pharmacy <sup>e</sup>	IMV (19)	16 (3)	74.3	70.0-85.3	65.6-96.3
	NIV >8hrs (8)	38(3)	39.3	20.8-89.3	2.3-139.2
	NIV ≤8hrs (11)	9 (1)	0.1	-	-
Dietetic <sup>e</sup>	IMV (19)	5 (1)	9.4	-	-
	NIV >8hrs (8)	25 (2)	3.3	2.4-4.1	1.6-5.0
	NIV ≤8hrs (11)	27(3)	4.6	3.2-8.1	1.9-11.6
Speech & language <sup>e</sup>	IMV (19)	42 (8)	41.0	27.4-65.7	9.3-86.3
	NIV >8hrs (8)	13 (1)	207.9		
	NIV ≤8hrs (11)	27 (3)	10.6	5.5-24.2	0.4-37.9
Occupational therapy <sup>e</sup>	IMV (19)	26 (5)	27.4	19.0-40.3	13.9-53.5
	NIV >8hrs (8)	13 (1)	229.7	-	-
	NIV ≤8hrs (11)	36 (4)	5.4	1.4-20.3	0.0-50.7
Physiotherapy <sup>e</sup>	IMV (19)	16 (3)	29.0	15.1-60.3	1.1-91.6
	NIV >8hrs (8)	38 (3)	5.0	3.4-22.2	1.7-39.3
	NIV ≤8hrs (11)	36 (4)	8.9	7.0-22.1	5.0-58.0
Clinical Psychology <sup>e</sup>	IMV (19)	16 (3)	31.2	20.7-38.8	10.1-46.5
	NIV >8hrs (8)	13 (1)	90.5	-	-
	NIV ≤8hrs (11)	0 (0)	-	-	-
Social Work <sup>e</sup>	IMV (19)	5 (1)	13.9	-	-
	NIV >8hrs (8)	0(0)	-	-	-
	NIV ≤8hrs (11)	63 (19	0 (0)	-	-
Nursing <sup>e</sup>	IMV (19)	26 (1)	11.7	7.0-13.9	1.1-41.6
	NIV >8hrs (8)	38 (3)	39.3	21.7-112.4	4.0-185.6
	NIV ≤8hrs (11)	27 (3)	6.4	6.1-7.6	5.7-8.7
Environmental /	IMV (19)	42 (8)	45.7	34.1-60.4	15.3-79.1
Housing Risk	NIV >8hrs (8)	25 (2)	70.3	65.2-75.3	60.2-80.3
assessment	NIV ≤8hrs (11)	18 (2)	57.8	47.2-68.4	36.6-79.1

<sup>c</sup> For one child, a barrier to discharge was difficulty in obtaining a date for a meeting.

<sup>d</sup> No document was solely prepared as a written discharge plan, but it was evident that the multidisciplinary discharge planning meeting outlined a discharge plan in the form of meeting minutes or summary.

<sup>e</sup> It was difficult to obtain a timeline for healthcare assessments as few were documented in medical or discharge notes. For 95% (36/38) of cases there was at least one recorded assessment.

#### STAGE 4/5: timescale 4 - 16 weeks from admission to RBHSC

Details regarding the home care package were held with the Home Care Trusts and were not maintained at RBHSC, thus these data do not provide a complete picture of timescales. In 13% of cases (5/38), for which data were available on both care package request and approval for the same child, the median time interval was 15.1 weeks (IQR 11.54-17.95, range 10.96-32.62). The time to arrange a care package consumed the 16 week period to discharge a child with complex needs.

Table 8. Timescale (median time, IQR & range in weeks) for securing care package from available dates in medical & discharge notes. [dash = no cases]

Discharge	Respiratory	% (n) notes	Median length	IQR 25-75%	Range
step	support	with date	of time (weeks)	(weeks)	(weeks)
Care package	IMV (19)	42 (8)	27.7	14.6-35.0	8.1-55.5
request	NIV ≤8hrs (11)	9 (1)	110.2	-	-
	NIV >8hrs (8)	0 (0)	-	-	-
Care package	IMV (19)	37 (7)	45.5	25.6-50.1	11.3-73.2
approval <sup>f</sup>	NIV ≤8hrs (11)	0 (0)	-	-	-
	NIV >8hrs (8)	0 (0)	-	-	-

After approval of the home care package, steps are taken to recruit and train carers and prepare for discharge. Table 9 outlines the average times taken to achieve completion of these steps.

Table 9. Timescale (median time, IQR & range in weeks) for steps in Stages 4 and 5 following care package approval [dash = no cases]

Discharge step	Respiratory	% (n)	Median	IQR 25-	Range
	support	notes	(weeks)	75%	(weeks)
		with		(weeks)	
		date			
Carer recruitment	IMV (19)	32 (6)	37.6	28.6-55.1	14.2-72.0
	NIV >8hrs (8)	0 (0)	-	-	-
	NIV ≤8hrs (11)	0 (0)	-	-	-
Carer interview	IMV (19)	16(3)	54.0	27.0-67.5	0.0-81.1
	NIV >8hrs (8)	0 (0)	-	-	-
	NIV ≤8hrs (11)	0 (0)	-	-	-
Carer in post	IMV (19)	47 (9)	43.3	33.0-65.2	23.2-73.0
	NIV >8hrs (8)	0 (0)	-	-	-
	NIV ≤8hrs (11)	9 (1)	50.3	-	-
Carer competent	IMV (19)	21 (4)	73.0	61.3-78.1	37.3-82.6
	NIV >8hrs (8)	0 (0)	-	-	-
	NIV ≤8hrs (11)	9 (1)	58.0	-	-
Parent training	IMV (19)	58 (11)	30.2	8.9-39.2	6.1-83.2
initiated <sup>g</sup>	NIV >8hrs (8)	38 (3)	12.0	7.4-102.5	2.7-193.0
	NIV ≤8hrs (11)	18 (2)	63.6	32.4-94.8	1.1-126.1
Parent	IMV (19)	53 (10)	41.8	24.3-50.7	10.4-79.1
competent	NIV >8hrs (8)	38 (3)	5.1	4.3-8.6	3.4-12.0
	NIV ≤8hrs (11)	27 (3)	34.9	23.1-82.8	11.3-130.8
Equipment list	IMV (19)	42 (8)	41.7	13.2-50.1	11.3-73.2
drawn up	NIV >8hrs (8)	25 (2)	9.8	7.0-12.6	4.1-15.4
	NIV ≤8hrs (11)	0 (0)	-	-	-
Equipment	IMV (19)	53 (10)	41.8	24.3-50.7	10.4-79.1
ordered	NIV >8hrs (8)	13 (1)	4.1	-	-
	NIV ≤8hrs (11)	42 (8)	46.2	29.9-63.0	21.4-81.1
Equipment	IMV (19)	11 (2)	55.2	51.7-58.7	48.2-62.2
service contract	NIV >8hrs (8)	0 (0)	-	-	-
arranged	NIV ≤8hrs (11)	0 (0)	-	-	-

Medical summary	IMV (19)	37 (7)	15.0	9.9-16.9	4.9-18.7
written <sup>h</sup>	NIV >8hrs (8)	13 (1)	55.5	-	-
	NIV ≤8hrs (11)	27 (3)			
Medical summary	IMV (19)	37 (7)	33.9	28.3-61.4	1.1-79.5
signed-off	NIV >8hrs (8)	13 (1)	55.5	-	-
	NIV ≤8hrs (11)	27 (3)	15.9	10.4-17.3	4.9-18.7
Emergency	IMV (19)	21 (4)	51.3	41.5-65.5	41.3-79.1
services notified	NIV >8hrs (8)	0 (0)	-	-	-
	NIV ≤8hrs (11)	0 (0)	-	-	-
Transport	IMV (19)	37 (7)	48.7	37.6-71.8	26.0-79.1
adapted <sup>i</sup>	NIV >8hrs (8)	0 (0)	-	-	-
	NIV ≤8hrs (11)	9 (1)	10.4	-	-
Informed	IMV (19)	0 (0)	-	-	-
car/house	NIV >8hrs (8)	0 (0)	-	-	-
insurance	NIV ≤8hrs (11)	9 (1)	37.3	-	-
Trial or phase in	IMV (19)	47 (9)	49.9	33.5-63.2	14.9-79.1
discharge home <sup>j</sup>	NIV >8hrs (8)	25 (2)	2.9	1.9-3.9	0.9-4.9
	NIV ≤8hrs (11)	18 (2)	71.5	40.3-102.6	9.1-133.8
Fast track	IMV (19)	42 (8)	59.5	34.6-81.3	14.2-97.1
card/follow up	NIV >8hrs (8)	25 (2)	9.4	7.2-11.7	5.0-13.9
plan <sup>k</sup>	NIV ≤8hrs (11)	18 (2)	13.3	12.0-14.6	10.7-15.9

<sup>9</sup> Training often relies on availability of healthcare staff in tertiary hospital units and within the community.

<sup>h</sup> A medical summary should be provided at readmissions. For the purpose of this audit a medical summary was interpreted as the discharge summary letter as a formalised medical summary was not available. Figure 14 shows that discharge summary letters were more frequent in records during the last five years.

<sup>i</sup> For children with more complex needs, car modifications are required. Delays to discharge recorded in 5% (2/38) of cases were caused by problems in transport arrangement to home and car modification requirements.

<sup>j</sup> In many cases there was a phased trial to visit home while waiting for the completion of steps within the discharge process, for example additional carer training.

<sup>k</sup> This plan explains what to do in the event of the child being unwell and should be available to and discussed with parents.



Figure 14. The number of children discharged with 'medical summaries' prior to and during the last five years.

#### Respite care

The Discharge Pathway stated the need for possibilities for respite care to cover, for example, sick leave, holidays and to provide parental time out. Respite was arranged prior to discharge in 68% (26/38) of records: 63% (12/19) for those requiring IMV; 75% (6/8) for >8 hours of NIV; and 45% (5/11) for ≤8 hours of NIV. From the 26/38 cases where respite was arranged, 50% (13/26) mentioned the type of respite arranged, 85% (11/13) recorded the NI Hospice and 15% (2/13) named other services e.g. a child minder and a DGH (Figure 15).



Figure 15. Type of respite care arranged prior to discharge for children requiring different types of respiratory support (*n*=13 recorded cases).

#### Contact after Discharge

The Discharge Pathway recommended follow-up with children and their famillies following discharge due to the vulnerability of their condition and risk of an untoward event. From the medical and discharge coordinator notes *were this was recorded (26%, 10/38),* follow-up was conducted at a median of 3. 8 weeks (IQR 1.2-9.3, 0.3-35.7) with families. This was out with the one week target set in the draft Discharge Pathway. Community paediatrician visits were recorded in 8% (3/38) cases and a telemedicine link was set up in 3% (1/38) of cases.

Table 10 shows the average contact time for children according to their LTV requirement.

Contact after	Respiratory	% (n)	Median	IQR	Range (weeks)
Discharge	support		time	(weeks)	
			(weeks)		
	IMV (n=19)	37 (7)	2.9	2.0-14.5	0.3-35.7
	NIV >8hrs	13 (1)	9.9	-	-
	(n=8)				
	NIV ≤8hrs	9 (1)	4.7	-	-
	(n=11)				

Table 10. The time to contact with family and child requiring LTV after discharge

## LIMITATIONS OF THE AUDIT

- Not all data could be obtained because information on the discharge process was not centralised.
- Staff involved in the Discharge Pathway held information relating to their own discipline in separate records.
- The minutes of multidisciplinary discharge meetings attempted to document progress in the Discharge Pathway, but reports and dates of completed steps were not always recorded.
- Management of care planning, which was the responsibility of community staff, was not recorded in the child's medical or discharge notes, but kept separately by the community trust. This included information on the home care package.
- Copies of community Trust documentation were not shared with the health care Trust from which the child was discharged.
- Children's social care notes are not copied to medical records or discharge coordinator

#### Recommendations

- 1) The discharge process should
  - a) record dates of key steps in the discharge process that have been initiated and completed
  - b) consolidate patient information from both hospital and community to ensure a stream lined discharge process.
  - c) develop an electronic centralised patient record system to facilitate the discharge process to include

- > assessments and healthcare provider consultations
- ➤ training
- funding applications
- discharge medical summary

#### 2) Contact information

- a) A core list of important healthcare provider contact information relevant for the child's discharge should be created. The core list should include those with a formalised role in the Discharge Pathway that need to attend discharge meetings e.g. community children's nurses
- b) A list should also be compiled to include those that simply need to be informed that the patient will be discharged from hospital and of their needs within community care e.g. GP
- 3) **Development of a new Medical Summary template** to replace the discharge letter for parents and key community staff to include;
  - a) details for planned discharge
  - b) essential medical, care information and prescriptions,
  - c) contact details for consultant at RBHSC and
  - d) contact phone numbers in case of events after discharge.
- 4) A strategy for closer communication and alignment of the discharge and funding application for home care support
  - a) the assessment process for home discharge should be on a tighter timeframe because funding applications require all assessments to be completed and clear documentation of the needs of the family
  - b) review the process of how home care packages are established
  - c) consider early review of home care packages as needs change over time
  - d) consider how costs are shared between hospital and community.
- 5) Review and revise the carer recruitment process for patients with complex conditions.
- 6) Revise the draft Discharge Pathway timescales.

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# APPENDIX 1: FOCUSED SET OF STANDARDS

Standard Focus (as per	Proposed timeframe for	Set Target (%)
Draft RBHSC Care Pathway	completion of discharge	
and confirmed by staff)	step (weeks)	
Home discharge	20	90
Inform the Discharge Co-ordinator (or equivalent) for the Child's home Trust	2	100
Notify Child's home trust and community services	2	100
Discharge meeting	4	100
Estimated discharge date agreed	4	100
Plan agreed for training and accountability	4	100
Equipment list made	4	100
Meeting with parents	4	100
Risk assessment of environment of home	4	100
Medical referrals made	4	100
Emergency services, car/house insurance & electricity provider notified	8	100
Readmission plan	8	100
Medical assessments complete	8	100
Care package request made	8	100
Care package agreed	12	80
Parent training started	12	100
Carer recruitment started	13	80
Equipment order placed	14	100
Equipment service contract agreed	14	90
One Day trial or in-phase for discharge to home	16	100
Parents competent	16	90
Carers interviews	16	90
Carers in post	18	90
Medical summary	18	90
Carers competent at required level	20	100
Medical summary signed off	20	100
Contact with parents after child is discharged home	1 week with discharge home	100

# APPENDIX 2 : AUDIT FORM

# Audit: Hospital discharge for children on long-term ventilation

Sample Identification number	
Characteristics	
Gender (delete applicable item)	1. Male 2. Female
Year of birth	
Diagnosis	1. Neuromuscular         (1) Duchenne         (2) Becker         (3) SMA1         (4) SMAA2         (5) SMA3         (6) Nemaline ROS         (7) Central Core Myopathy         (8) Other         2. Airway abnormalities         (1) Upper airway         (2) Tracheal         (3) Bronchial         3. Abormalities in control of breathing         4. Spinal cord injury         5. Chronic Lung Disease of Prematurity         6. Chronic Lung Disease         7. Other
GP's BT code	BT
<b>Co-morbidities</b> (list)	<ol> <li>Congential heart disease</li> <li>Genetic syndrome</li> <li>Development delay</li> <li>Prematurity</li> <li>Others</li> </ol>
Ventilation via tracheostomy on discharge	<ol> <li>Yes</li> <li>No</li> <li>If No, other interface used if not tracheostomy</li> </ol>
Time dependent on ventilatory assistance	<ol> <li>Less tha 6 hrs/daytime use</li> <li>Night-time</li> <li>More than 18 hrs</li> </ol>
Discharge settings on Mode home ventilator	1. CPAP (continuous positive airway pressure)

		2. 3.	BiPAP (bilevel positive airway pressure) other
	On oxygen?	1.	Yes 2. No
		lf 	Yes, what is the O <sub>2</sub> requirement%
	P <sub>co2</sub> levels		
At discharge carriage of ventilator support?		1.	Adapted buggy
		2.	Wheelchair
		3. 4.	Backpack Other
Was GP/health visitor made aware of discharge plan ?		1.	Yes 2. No
		1.	Home Foster Care
Discharged to		2. 3.	Other hospital (specify)
		4. 5.	Children's Hospice Other (specify)
Respite care organised		1. If Y 1. 2.	Yes 2. No es, with Hospice Other (specify)

Time lines

Date			dd/mm/yyyy
Admission to PICU or ward			
Tracheostomy (if applicable)			
Decision to discharge with ventilation			
Discharge from PICU to ward (if applicable)			
Referral to Discharge coordinator/lead communit	y nurse		
Discharge multi-disciplinary meeting			
	GP		
	Health visitor		
Community services notified	Social worker		
	Education (if applicable)		
	Home Trust		
Proposed discharge date			
Meeting with parents			
A written plan of training and accountability agreed			
Educational Psychology referral			
Pharmacy assessment			
Dietetic assessment			
Speech & language assessment			
Occupational therapy assessment			
Physiotherapy assessment			
Clinical psychology assessment (if applicable)			
Social Work assessment			
Nursing Assessment			
Care package request			
Care package agreed			
	List checked		
Equipment	Order placed		
	Service contract agreed		
Housing & risk management review			
	Started		
Home Carers recruitment	Interviews		
	In post		

	Competent at required level	
Parent training	Started	
	Competent	
Full medical summary with 24 hr contac	t Written	
telephone number	Signed off	
Emergency, electrical & telephone services not	fied	
Transport adapted e.g. car		
Car / house insurance informed		
1 Day trial or phase-in started for discharge to	nome	
Actual Discharge from hospital to home / to ot	her facility	
Last contact with patient & family after dischar	ge by hospital discharge co-ordinator	
'Fast Track' card for re-admissions given / Re- medical input		
Listed barriers to discharge	l.	
	2.	
	3.	

Additional Comments:

# APPENDIX 3 : PROJECT TEAM AND ROLE WITHIN AUDIT

Name	Job Title/Specialty	Trust	Role
Bronagh Blackwood	Senior Lecturer	QUB	Substantial contribution to the conception and design of the audit; coordinated the audit project; co-chaired meetings; co-edited the final audit report
Dara O'Donoghue	Consultant Respiratory Physician	BHSCT	Substantial contribution to the design of the audit form; provided expert contributions to meetings, report and audit plan.
Gary Doherty	Consultant Respiratory Physician	BHSCT	Substantial contribution to the design of the audit form; provided expert contributions to meetings, report and audit plan.
Michael Shields	Consultant Respiratory Physician	BHSCT	Substantial contribution to the conception and design of the audit; provided expert contributions to meetings, report and audit plan; co-chaired meetings.
Julie Ramsey	Regional Discharge Liaison Nurse	BHSCT	Contributed to the design of the audit form; provided expert contributions to meetings, report and audit plan. Facilitated data collection.
Debbie Hewitt	Regional Discharge Liaison Nurse	NHSCT	Contributed to the design of the audit form; provided expert contributions to meetings, report and audit plan. Facilitated data collection.
Julie Chambers	Regional Discharge Liaison Nurse	SEHSCT	Contributed to the design of the audit form; provided expert contributions to meetings, report and audit plan. Facilitated data collection.
Barbara Maxwell	Respiratory Support Nurse Specialist	BHSCT	Contributed to the design of the audit form; provided expert contributions to meetings, report and audit plan. Facilitated data collection.
Isobel Douglas	Neuromuscular Support Nurse Specialist	BHSCT	Contributed to the design of the audit form; provided expert contributions to meetings, report and audit plan. Facilitated data collection.
Jennifer Bell	Research Fellow	QUB	Substantial contribution to the conception and design of the audit; collected data; organised meetings; co-edited the final audit report.

# APPENDIX 4: ADDITIONAL TABLES

Table 1. The number and current age of children requiring on long-term ventilation in Northern Ireland.

Age Group (years)	No. of children
<5	12
5-10	15
11-15	8
16-19	11
>19	1
Total	47

Table 2. The comorbidities of children requiring LTV recorded in medical notes (n=26/47)

Age Group (years)	No. of children
Congenital heart disease	2
Genetic syndrome	2
Developmental delay	9
Prematurity	1
Others e.g. epilepsy, trisomy	12