Long-term ventilation: Lead clinician (ongoing care) questionnaire

A. INTRODUCTION

What is this study about?
The aim of this study is to identify remediable factors in the care of patients who are receiving, or have received, long-term ventilation (LTV) before their 25th Birthday.

Inclusions:
Data has been collected on patients up to their 25th birthday who were receiving, or who had received, long-term ventilation between 1st April 2016 – 31st March 2018.

Long-Term Ventilation is defined as 'ventilation provided every day for 3 months (invasive and non-invasive) where the intention is/was to maintain the patient at home on continued ventilator support (not home oxygen)'

Who should complete this questionnaire?
This form should be completed by a member of the clinical team who leads the long term care of the patient; this may be a clinician, physiotherapist or nurse. This form should be completed in relation to the status of the patient/care received as of the 31/03/2018. If the patient was discharged from the LTV service prior to the 31/03/2018, please complete this form in relation to their last appointment/attendance prior to discharge.

Questions or help?
A list of definitions can be found here: https://www.ncepod.org.uk/ltv.html
If you have any queries about this study or this questionnaire, please contact: ltv@ncepod.org.uk or telephone 020 7251 9060

CPD accreditation:
Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Child Health.

B. LEAD CLINICIAN/TEAM DETAILS

1a. Are you the lead LTV clinician/team providing the patient's usual LTV care?

◯ Yes ◯ No ◯ Unknown

1b. If answered "No" to [1a] then:
If NO, please provide details of the HOSPITAL/SITE where the patient's usual lead LTV clinician is based, and return this questionnaire to NCEPOD: (Please do not supply clinician names)

1c. If answered "No" to [1a] then:
If NO, please provide details of the TRUST where the patient's usual lead LTV clinician is based, and return this questionnaire to NCEPOD: (Please do not supply clinician names)

2. If answered "Yes" to [1a] then:
Please provide the address of the main community team:
Please do not supply any clinician names

If you are not the lead clinician or part of the team who leads the long term care of the patient, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD

C. CLINICIAN DETAILS AND STRUCTURED COMMENTARY

1a. Professional grade

1b. Grade:

1c. Specialty

2. Please use the box below to provide a brief summary of this case, adding any additional comments or information you feel relevant. You should be assured that this information is confidential. NCEPOD attaches great importance to this summary. Please give as much information as possible about the care of this patient.

D. RECENT HOSPITAL ADMISSION DETAILS

1a. Did the patient have an admission to this hospital between the 01/04/2016 – 31/03/2018?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
If YES, please specify the date of the most recent admission between the 01/04/2016 – 31/03/2018:

1c. If answered "Yes" to [1a] then:
If YES, please specify the time of the most recent admission between the 01/04/2016 – 31/03/2018:

1d. If answered "Yes" to [1a] then:
If YES, was a tracheostomy insertion undertaken during this admission?

◯ Yes ◯ No ◯ Unknown

1e. If answered "Yes" to [1a] then:
If YES, please specify the type of ventilation received prior to admission?

◯ Invasive ◯ Non-invasive ◯ Unknown

E. PATIENT SPECIFIC DETAILS

1a. Was the patient under the age of two on 31/03/2018?

◯ Yes ◯ No ◯ Unknown

1b. If answered "No" to [1a] then:
If NO, please specify the age of the patient on 31/03/2018:

Years ☐ Unknown

1c. If answered "Yes" to [1a] then:
If YES, please specify the age of the patient on 31/03/2018:

Months ☐ Unknown

2a. Was the patient under the age of two when LTV began?

◯ Yes ◯ No ◯ Unknown

2b. If answered "No" to [2a] then:
If NO, please specify the age of the patient when LTV began:

Years ☐ Unknown

2c. If answered "Yes" to [2a] then:
If YES, please specify the age of the patient when LTV began:

Months ☐ Unknown

3a. Please specify the date when LTV began:

3b. How long had the patient been on LTV in total at 31/03/2018?

Years ☐ Unknown

4a. Please specify the type of LTV received on the 31/03/2018:

◯ Invasive ◯ Non-invasive ◯ Unknown ◯ Other

4b. If answered "Other" to [4a] then:
If OTHER, please specify:

4c. What was the level of dependency on LTV as of the 31/03/2018?
Please see definitions

◯ High (Level 1) ◯ Severe (Level 2) ◯ Priority (Level 3) ◯ Unknown

4d. What was the number of hours of ventilator-free breathing per day as of the 31/03/2018?

☐ Unknown

5. Gender

◯ Male ◯ Female ◯ Unknown

6. Weight at the time of LTV initiation?

kg ☐ Unknown

F. PATIENT CONDITION PRIOR TO LTV

1. What were the main underlying system failure (s) which led to this patient needing LTV? (Please tick all that apply)

- ☐ Respiratory muscle weakness
- ☐ Upper airway obstruction
- ☐ Spinal cord injury
- ☐ Neurodisability
- ☐ Central drive
- ☐ Skeletal deformity e.g. Scoliosis
- ☐ Obesity hypoventilation

Please specify any additional options here...

2. When LTV was commenced was it:

- ◯ As a bridge to definitive therapy or in anticipation of recovery with growth
- ◯ As “Destination” therapy (with no immediate plan to discontinue)
- ◯ Unknown

If not listed above, please specify here...

G. DECISION TO COMMENCE LTV

1. Was LTV commenced between 1st April 2016 – 31st March 2018?

◯ Yes ◯ No ◯ Unknown

Where LTV was commenced during the 2 year study period:

It is understood that the decision to provide LTV to a patient is a process and that the timing of specific decisions and events may be difficult to provide accurately in retrospect. Patients may be ventilated for some period before a formal decision to provide LTV is made or there may be evidence of deteriorating respiratory function. We would ask that clinicians provide information with as much accuracy as possible and refer to clinical records from the time

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2. If answered "Yes" to [1] then:
Is there a clear record of how and when the decision to commence LTV was made?

◯ Yes ◯ No ◯ Unknown

3. If answered "Yes" to [1] then:
How was the decision made to commence LTV?

4a. If answered "Yes" to [1] then:
Was a multi-professional meeting held to discuss the initiation of LTV?

◯ Yes ◯ No ◯ Unknown

4b. If answered "Yes" to [1] then:
Was the patients GP informed of the LTV decision prior to the patient leaving this unit?

◯ Yes ◯ No ◯ Unknown

5. If answered "Yes" to [1] then:
Were the implications of long-term ventilation at home discussed with the parent/carers?

◯ Yes ◯ No ◯ Unknown

6a. If answered "Yes" to [1] then:
Have there been occasions during your care of this patient when there have been significant differences of opinion between clinicians about whether LTV was an appropriate treatment modality?

◯ Yes ◯ No ◯ Unknown

6b. If answered "Yes" to [6a] and "Yes" to [1] then:
If YES, please give details:

6c. If answered "Yes" to [6a] and "Yes" to [1] then:
If YES, how were these resolved? (Please tick all that apply)

- ☐ Involvement of a Clinical ethics committee
- ☐ Formal multidisciplinary discussion
- ☐ Within hospital second opinion
- ☐ Unknown
- ☐ External Mediation
- ☐ Informal multidisciplinary discussion
- ☐ Remain unresolved

Please specify any additional options here...

7a. If answered "Yes" to [1] then:
Have there been occasions during your care of this patient when there have been significant differences of opinion between clinicians and the parent carer and/or patient about whether LTV was the appropriate treatment modality?

- ○ Yes
- ○ No
- ○ Unknown

7b. If answered "Yes" to [7a] and "Yes" to [1] then:
If YES, please give details:

7c. If answered "Yes" to [7a] and "Yes" to [1] then:
If YES, how were these resolved? (Please tick all that apply)

- ☐ Involvement of a Clinical ethics committee
- ☐ External Mediation
- ☐ External Mediation Formal multidisciplinary discussion
- ☐ Informal multidisciplinary discussion
- ☐ Within hospital second opinion
- ☐ Remain unresolved
- ☐ Unknown

Please specify any additional options here...

LTV DETAILS

8a. If answered "Yes" to [1] then:
Prior to initiation had the need for LTV been anticipated?

◯ Yes ◯ No ◯ Unknown

8b. If answered "Yes" to [1] and "Yes" to [8a] then:
If YES, what was the original planned type of LTV?

◯ Invasive ◯ Non-invasive ◯ Unknown

ANTICIPATED LEVEL OF DEPENDENCY ON LTV

9a. If answered "Yes" to [1] then:
At the time of initiation, what was the anticipated level of dependency on LTV?
Please see definitions

◯ High (Level 1) ◯ Severe (Level 2) ◯ Priority (Level 3) ◯ Unknown

9b. If answered "Yes" to [1] then:
At the time of initiation, what was the anticipated number of hours of ventilator free breathing per day?

Hours ☐ Unknown

9c. If answered "Yes" to [1] then:
Did this level of dependency change during the process of initiating LTV?

◯ Yes ◯ No ◯ Unknown

H. EQUIPMENT

1. Which of the following equipment was available to the patient in their usual place of residence? (Please tick all that apply)

- ☐ Backup (second) ventilator
- ☐ Ventilator battery pack
- ☐ Oxygen saturation monitor
- ☐ Hand-held saturation monitor
- ☐ Self inflating bag
- ☐ Suction equipment
- ☐ Humidification equipment
- ☐ Carbon dioxide monitoring equipment
- ☐ Access to a replacement ventilator within 24 hours
- ☐ Cough assist
- ☐ Tracheostomy safety box
- ☐ Oxygen supply
- ☐ Nebuliser
- ☐ None
- ☐ Unknown

Please specify any additional options here...

2a. What ventilator was chosen to deliver LTV?
Please specify make & model

2b. Does your service/network use this ventilator for all patients on long-term ventilation?

◯ Yes ◯ No ◯ Unknown

2c. If answered "No" to [2b] then:
If NO please give reasons for the use of different models:

3a. Was a ventilator service contract in place for this patient?

◯ Yes ◯ No ◯ Unknown

3b. Do you know the date of the last ventilator service?

◯ Yes ◯ Not available ◯ Not recorded ◯ Unknown

3c. If answered "Yes" to [3b] then:
What was the date of the last ventilator service?

4a. Were there any known equipment issues?

◯ Yes ◯ No ◯ Unknown

4b. If answered "Yes" to [4a] then:
If YES, please give details:

I. COMMUNITY CARE ARRANGEMENTS

1. Who was responsible for care provision in the community?

- ☐ Registered healthcare staff (NHS)
- ☐ Carers (NHS)
- ☐ Family/parent carers
- ☐ No care provision
- ☐ Registered healthcare staff (other provider)
- ☐ Carers (other provider)
- ☐ Self care
- ☐ Unknown

Please specify any additional options here...

2. Which of the following did the patient have access (in the community) to?

- ☐ Tracheostomy specialist
- ☐ Speech & language therapist
- ☐ None
- ☐ Physiotherapist
- ☐ Nutritional support/dietetics
- ☐ Occupational therapist
- ☐ Unknown

Please specify any additional options here...

3a. Was there any failure of community care provision/breakdown of arrangements in the previous three months?

- ○ Yes
- ○ No
- ○ Unknown

3b. If answered "Yes" to [3a] then:
If YES, please give details:

J. OUTPATIENT REVIEWS

We are aware that models of care vary, i.e. outreach services/satellite services/home reviews. Please answer the following questions in relation to the last routine review (non-emergency)

1a. What was the date of the last outpatient review?

1b. Which of the following assessments were made at this review

- ☐ Clinical assessment
- ☐ Blood gas analysis
- ☐ Overnight oximetry
- ☐ Overnight polysomnography
- ☐ Pulmonary function testing
- ☐ Care plan review
- ☐ Ventilator data
- ☐ None
- ☐ Unknown

Please specify any additional options here...

2. How many outpatient LTV reviews took place over the 12 months prior to the 31/03/2018?

☐ Unknown

K. TRANSITION

1. As of the 1st April 2016, was this patient aged 14 or older?

◯ Yes ◯ No ◯ Unknown

2a. If answered "Yes" to [1] then:
Were/have plans been made to transition this patient from paediatric to adult services?

◯ Yes ◯ No ◯ Unknown

2b. If answered "Yes" to [1] and "Yes" to [2a] then:
If YES, was/has a lead clinician for LTV care been clearly identified?

◯ Yes ◯ No ◯ Unknown

3. If answered "Yes" to [1] then:
Was there an MDT meeting where a transition plan was agreed?

◯ Yes ◯ No ◯ Unknown

4a. If answered "Yes" to [1] then:
Was the patient reviewed in a joint paediatric transition clinic?

◯ Yes ◯ No ◯ Unknown

4b. If answered "Yes" to [1] and "No" to [4a] then:
If NO, why not?

☐ No transition clinic

Please specify any additional options here...

5a. If answered "Yes" to [1] then:
Did the patient transition from paediatric to adult care between the 1st April 2016 – 31st March 2018?

◯ Yes ◯ No ◯ Unknown

5b. If answered "Yes" to [1] and "Yes" to [5a] then:
If YES, did any problems arise?

◯ Yes ◯ No ◯ Unknown

5c. If answered "Yes" to [1] and "Yes" to [5a] and "Yes" to [5b] then:
If YES, please give details:

L. OVERALL CARE

1a. In retrospect, between the 1st April 2016 – 31st March 2018, was there any aspect of the long-term LTV care that could have been improved?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
If YES, please give further details:

Many thanks for taking the time to complete this questionnaire