Long-term ventilation: Community team 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 the clinician or team who leads the long-term community care of the patient. 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. COMMUNITY TEAM DETAILS

1a. Are you part of the main community team providing the patient’s usual LTV community care?

◯ Yes ◯ No ◯ Unknown

1b. If answered "No" to [1a] then:
If NO, please provide details of the SITE where the patient’s usual LTV community team 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 (if applicable) where the patient’s usual LTV community team is based, and return this questionnaire to NCEPOD: (Please do not supply clinician names)
This can be left blank if not applicable

If you are not part of the community 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. PATIENT DATA

1a. Was the patient under the age of 2 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

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2. Sex:

- ○ Male
- ○ Female
- ○ Unknown

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

- ○ Invasive
- ○ Non-invasive
- ○ Unknown

4a. What was the patients level of dependency on LTV? (As of 31/03/2018)
Please see definitions

- ○ High (Level 1)
- ○ Severe (Level 2)
- ○ Priority (Level 3)

4b. What was the number of hours of ventilator-free breathing per day? (As of 31/03/2018)

[Hours] ☐ Unknown

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

[Years] ☐ Unknown

E. COMMUNITY CARE ARRANGEMENTS

1. Who was responsible for care provision in the community? (Please tick all that apply)

- ☐ 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...

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2. Which of the following did the patient have access to in the community? (Please tick all that apply)

- ☐ Tracheostomy specialist
- ☐ Speech & language therapist
- ☐ Physiotherapist
- ☐ Nutritional support/dietetics
- ☐ Occupational therapist
- ☐ Unknown

Please specify any additional options here...

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

○ Yes ○ No ○ Unknown

2b. Do you know the date of the last ventilator service?

○ Yes ○ No ○ Not recorded ○ Unknown

2c. If answered "Yes" to [2b] then:
What was the date of the last ventilator service? (Prior to the 31/03/2018)

3a. Were there any known equipment issues?

○ Yes ○ No ○ Unknown

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

G. TRAINING

1a. Have you/the community team received training on the use of the patient’s ventilator?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
If YES are there are urgent/emergency situations which relate to the patient’s ventilator which you have been trained to manage?

◯ Yes ◯ No ◯ Unknown

1c. If answered "Yes" to [1a] then:
If YES how would support be provided to this patient in an emergency? (Please tick all that apply)

☐ Manual ventilation
☐ Call/Link with LTV centre direct
☐ Change to second ventilator
☐ Unknown

Please specify any additional options here...

2a. Are you/the community team responsible for daily maintenance and safety checks on the ventilator and associated equipment?

◯ Yes ◯ No ◯ Unknown

2b. If answered "No" to [2a] then:
If NO, who is responsible for daily checks?

H. TRACHEOSTOMY VENTILATION

1. Is this patient tracheostomy ventilated?

○ Yes ○ No ○ Unknown

2. If answered "Yes" to [1] then:
Does the patient have access to a tracheostomy nurse specialist in the community?

○ Yes ○ No ○ Unknown

3. If answered "Yes" to [1] then:
Are you/the community team responsible for daily safety checks on tube patency and position?

○ Yes ○ No ○ Unknown

4a. If answered "Yes" to [1] then:
Where are planned tracheostomy tube changes generally undertaken for this patient? (Please tick all that apply)

☐ In hospital ☐ At home ☐ Unknown

Please specify any additional options here...

4b. If answered "Yes" to [1] and "In hospital" to [4a] then:
If IN HOSPITAL, please specify within which area of care:

☐ Ward ☐ Clinic or ambulatory care ☐ Unknown

Please specify any additional options here...

4c. If answered "Yes" to [1] and "In hospital" to [4a] then:
If IN HOSPITAL, is there is a plan for training to be provided to the family?

○ Yes ○ No ○ Unknown

4d. If answered "Yes" to [1] and "In hospital" to [4a] and "Yes" to [4c] then:
If YES, is there a plan to provide tube changes in the future at home?

○ Yes ○ No ○ Unknown

4e. If answered "Yes" to [1] and "At home" to [4a] then:
If AT HOME, what training and support was/is provided? (Please tick all that apply)

☐ On site nurse specialist nurse(s) always present
☐ Telephone advice ☐ Unknown

Please specify any additional options here...

I. EMERGENCY HEALTHCARE PLANNING

1a. Are you aware of a fast track/emergency health plan for this patient?

- ◯ Yes
- ◯ No
- ◯ Unknown

1b. If answered "Yes" to [1a] then:
If YES, do you retain a copy for the patient?

- ◯ Yes
- ◯ No
- ◯ Unknown

1c. If answered "Yes" to [1a] then:
If YES, is it regularly updated?

- ◯ Yes
- ◯ No
- ◯ Unknown

J. PROVISION OF OTHER SERVICES

1a. Does the community team provide any support to the child/young person at school or college?

○ Yes ○ No ○ Unknown

1b. If answered "Yes" to [1a] then:
If YES, what does this include?

K. COMMISSIONING AND CARE PLANS

1. How are services commissioned for this patient? (Please tick all that apply)

- ☐ Health care funded
- ☐ Social care funded
- ☐ Personal healthcare budget
- ☐ Private funding
- ☐ Insurance
- ☐ Charitable funding
- ☐ Unknown

Please specify any additional options here...

2a. Between the 1st April 2017 – 31st March 2018 was the personal care plan/support plan reviewed for this patient?

- ○ Yes
- ○ No
- ○ Unknown
- ○ NA – patient discharged from service prior to 2017

2b. If answered "Yes" to [2a] then:
If YES, were you included in the outcome and any changes made after this review?

- ○ Yes
- ○ No
- ○ Unknown

L. TRANSITION

1a. Did the patient transition to adult services between 1st April 2016 – 31st March 2018?

○ Yes ○ No ○ Unknown

1b. If answered "Yes" to [1a] then:
If YES, did the commissioning arrangements change for this patient following transition to adult services?

○ Yes ○ No ○ Unknown

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

M. 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