

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.

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

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 organisations who provide community care for ≤ 18 years old. The person completing the form should have knowledge of this hospital/service's organisation of care.

Definitions

For definitions please follow the link below:

<https://www.ncepod.org.uk/pdf/current/HF/Definitions%20for%20website.pdf>

B. HOSPITAL DETAILS

1. Name of Trust/Health Board:

2. Does your Trust/Health Board provide care for tracheostomy-ventilated patients <18 years old?

- Yes No Unknown

3. Does your Trust/Health Board provide care for non-invasively ventilated patients <18 years old?

- Yes No Unknown

4. Which aspects of long-term ventilation are provided by your Trust/Health Board for patients <1 years old? (Please tick all the apply)

- Outpatient LTV management Community LTV provision None

5. Which aspects of long-term ventilation are provided by your Trust/Health Board for patients aged 1-18 years old? (Please tick all the apply)

- Outpatient LTV management Community LTV provision None

6. Which of the following categories of *ventilator dependent patients <18 years old does your Trust/Health Board provide LTV for? (Please tick all that apply)

**Please see definitions*

- High (level 1) Severe (level 2) Priority (level 3) None

C. NETWORKS OF CARE

1a. Is your Trust/Health Board part of a *formal network for LTV care?

**Please see definitions*

Yes

No

Unknown

NA

1b. If answered "No" to [1a] then:

If NO, is your Trust/Health Board part of an *informal network of care?

**Please see definitions*

Yes

No

Unknown

NA

1. Does your Trust/Health Board undertake annual audit in relation to LTV care for patients <18 years old?

- Yes
 No
 Unknown

2. Does your Trust/Health Board collect data on the number of patients <18 years old receiving LTV who are being for by the Trust/Health Board?

- Yes
 No
 Unknown

3. Does your Trust/Health Board keep a record of the total number of tracheostomy ventilated patients <18 years old?

- Yes
 No
 Unknown
 NA

4. Does your Trust/Health Board collect quality of life data on LTV patients <18 years old?

- Yes
 No
 Unknown

5. Does your Trust/Health Board collect data on whether the service(s) provided improved patient survival for patients <18 years old?

- Yes
 No
 Unknown

6a. How many tracheostomy-ventilated patients <18 years old were under your Trust/Health Board between 1st April 2016 - 31st March 2018?

If none, please use 0

Patients
 Unknown

6b. Is this number:

- Number of cases coded
 Routinely collected data by the Trust/Health Board
 An approximation

If not listed above, please specify here...

7a. How many non-invasively ventilated patients <18 years old were under your Trust/Health Board between 1st April 2016 - 31st March 2018?

patients
 Unknown

7b. Is this number:

- Number of cases coded
 Routinely collected data within your Trust/Health Board
 An approximation

If not listed above, please specify here...

1a. Does your Trust/Health Board have a guideline(s) for long-term ventilation in patients <18 years old?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

If YES, does this include: (Please tick all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> Ventilator management | <input type="checkbox"/> Consent | <input type="checkbox"/> Tracheostomy care |
| <input type="checkbox"/> Oxygen therapy | <input type="checkbox"/> Saturation monitoring | <input type="checkbox"/> Suction |
| <input type="checkbox"/> Resuscitation | <input type="checkbox"/> Unknown | |

Please specify any additional options here...

F. COMMUNITY LTV PROVISION

1. In the community, on average, how frequently do level *2 and *3 patients <18 years old receive review by a registered health care professional?

**Please see definitions*

- Daily At least weekly At least fortnightly
 At least monthly Less than monthly Unknown

If not listed above, please specify here...

2. Which of the following are available in the location where community care is delivered during normal working hours (9am-5pm)? (Please tick all that apply)

- Physiotherapy Occupational therapy
 Dietetics Speech and language therapy
 Home Oxygen Assessment and Review Service Unknown

Please specify any additional options here...

3. Which of the following are available in the location where community care is delivered outside of normal working hours? (Please tick all that apply)

- Physiotherapy Occupational therapy
 Dietetics Speech and language therapy
 Home Oxygen Assessment and Review Service Unknown

Please specify any additional options here...

4. Who takes responsibility for the maintenance of ventilation equipment?

- Community service Hospital service Private provider Unknown

If not listed above, please specify here...

G. VENTILATORS

1a. Has the Trust/Health Board had problems accessing appropriate equipment for LTV patients <18 years old?

Yes

No

Unknown

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

1a. For service users that transition between paediatric and adult services is there a local guideline for transition?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

If YES, does this guideline include guidance for community services?

- Yes No Unknown
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2. Are both health and social services included in the transition process?

- Yes No Unknown

I. COMMISSIONING ARRANGEMENTS

1. Are formal commissioning arrangements in place for community LTV provision within your Trust/Health Board?

Yes

No

Unknown

NA

Many thanks for taking the time to complete this questionnaire