

Long-term Ventilation Organisational Questionnaire: Paediatric Services (<18 years old)

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

Filtering

Filter questions have been added at the beginning of each section to ensure you only complete sections relevant to your hospital or service i.e. Hospital details, type of centres.

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 Hospital:

2. Name of Trust/Health Board:

3. Hospital details:

- | | |
|---|--|
| <input type="radio"/> DGH <500 beds | <input type="radio"/> DGH ≥500 beds |
| <input type="radio"/> Specialist Paediatric Tertiary Centre | <input type="radio"/> University Teaching Hospital |
| <input type="radio"/> Independent Hospital | <input type="radio"/> Community Hospital |

If not listed above, please specify here...

4. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

- ☐ *LTV Centre ☐ Other

5. Does this hospital provide care for tracheostomy-ventilated patients <18 years old?

- ☐ Yes ☐ No ☐ Unknown

6. Does this hospital provide care for non-invasively ventilated patients <18 years old?

- ☐ Yes ☐ No ☐ Unknown

7. Which aspects of long-term ventilation are provided at this hospital for patients <1 years old? (Please tick all the apply)

- ☐ LTV initiated
- ☐ Outpatient LTV management
- ☐ Elective admission of LTV patients
- ☐ Emergency department attendance (only received as an emergency in ED but not further admitted)
- ☐ Emergency admission (LTV ward)
- ☐ Emergency admission (critical care)
- ☐ Emergency admission (other ward)
- ☐ Community LTV provision
- ☐ None

8. Which aspects of long-term ventilation are provided at this hospital for patients aged 1-18 years old? (Please tick all the apply)

- ☐ LTV initiated
- ☐ Outpatient LTV management
- ☐ Elective admission of LTV patients
- ☐ Emergency department attendance (only received as an emergency in ED but not further admitted)
- ☐ Emergency admission (LTV ward)
- ☐ Emergency admission (Critical Care)
- ☐ Emergency admission (other ward)
- ☐ Community LTV provision
- ☐ None

9. Does this hospital have an emergency department?

- ☐ Yes ☐ No ☐ Unknown ☐ NA

10. Does the hospital have an emergency admission unit?

- ☐ Yes ☐ No ☐ Unknown ☐ NA

11. Please specify whether this hospital provides: (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Paediatric Critical Care unit beds - Level 1 | <input type="checkbox"/> Paediatric Critical Care unit beds - Level 2 |
| <input type="checkbox"/> Paediatric Critical Care unit beds - Level 3 | |
| <input type="checkbox"/> Adult (General) Critical Care unit beds - Level 2 | |
| <input type="checkbox"/> Adult (General) Critical Care unit beds - Level 3 | |
| <input type="checkbox"/> Neonatal Level 2 cots | <input type="checkbox"/> Neonatal Level 3 cots |
| <input type="checkbox"/> Adult LTV beds | <input type="checkbox"/> Paediatric LTV beds |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> NA |
| <input type="checkbox"/> None | |

12. If answered "*LTV Centre" to [4] then:

If this hospital provides LTV for both children and adults, are these services provided by:

- ☐ Separate neonatal, paediatric and adult LTV services
☐ A combined service (all age groups)
☐ Combined neonatal and paediatric service and separate adult service
☐ Unknown
☐ NA
☐ None

If not listed above, please specify here...

13. If answered "*LTV Centre" to [4] then:

Which of the following categories of *ventilator dependent patients <18 years old does your hospital provide LTV for? (Please tick all that apply)

**Please see definitions*

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

14. If answered "*LTV Centre" to [4] then:

In terms of LTV patients <18 years old, does this hospital have: (Please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Criteria for acceptance | <input type="checkbox"/> Exclusion criteria |
| <input type="checkbox"/> Criteria for complex vs general care | <input type="checkbox"/> Criteria for step up (general to complex care) |
| <input type="checkbox"/> Criteria for step down (complex to general care) | |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> None |

C. NETWORKS OF CARE

1a. Is the hospital part of a *formal network for LTV care?

**Please see definitions*

- ☐ Yes ☐ No ☐ Unknown

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

If NO, is the hospital part of an *informal network of care?

**Please see definitions*

- ☐ Yes ☐ No ☐ Unknown

2. Does the hospital have *formal transfer arrangements in place for LTV patients?

**Please see definitions*

- ☐ Yes ☐ No ☐ Unknown ☐ NA

3. If LTV patients require urgent transfer to paediatric critical care is the normal PCC transfer service commissioned and funded to provide this?

- ☐ Yes ☐ No ☐ Unknown ☐ NA

1. Is LTV initiated and/or outpatient management provided at this hospital site for patients <18 years old?

☐ Yes ☐ No ☐ Unknown

**2. If answered "Yes" to [1] then:
Does this LTV service undertake annual audit for patients <18 years old?**

☐ Yes ☐ No ☐ Unknown

**3. If answered "Yes" to [1] then:
Does this LTV service collect data on the number of patients <18 years old cared for by the service?**

☐ Yes ☐ No ☐ Unknown

**4. If answered "Yes" to [1] then:
Does this LTV service keep a record of the total number of tracheostomy ventilated patients <18 years old?**

☐ Yes ☐ No ☐ Unknown ☐ NA

**5. If answered "Yes" to [1] then:
Does this LTV service collect quality of life data on patients <18 years old?**

☐ Yes ☐ No ☐ Unknown

**6. If answered "Yes" to [1] then:
Does this service collect data on whether the LTV service(s) improve patient survival in patients <18 years old?**

☐ Yes ☐ No ☐ Unknown

**7a. If answered "Yes" to [1] then:
How many tracheostomy-ventilated patients <18 years old were under the LTV service between 1st April 2016 - 31st March 2018 in your hospital?**

If none, please use 0

patients ☐ Unknown

**7b. If answered "Yes" to [1] then:
Is this number:**

- ☐ Number of cases coded
☐ Routinely collected data within the department
☐ An approximation

If not listed above, please specify here...

**8a. If answered "Yes" to [1] then:
How many non-invasively ventilated patients <18 years old were under the LTV service between 1st April 2016 - 31st March 2018 in your hospital?**

If none, please use 0

patients ☐ Unknown

**8b. If answered "Yes" to [1] then:
Is this number:**

- ☐ Number of cases coded
- ☐ Routinely collected data within the department
- ☐ An approximation

If not listed above, please specify here...

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

- ☐ *LTV Centre ☐ Other

2a. If answered "*LTV Centre" to [1] then:

Does this service have a guideline(s) for long-term ventilation in patients <18 years old?

- ☐ Yes ☐ No ☐ Unknown

2b. If answered "*LTV Centre" to [1] and "Yes" to [2a] then:

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

- | | | |
|--|--|--|
| <input type="checkbox"/> Initiation of ventilation | <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...

3. If answered "*LTV Centre" to [1] then:

Which of the following are provided for LTV patients <18 years old who attend this hospital? (Please tick all that apply)

- ☐ A named lead consultant
- ☐ A nominated key worker
- ☐ An agreed personal care plan
- ☐ Arrangements for respite care
- ☐ Hospice admission for end of life care
- ☐ Escalation of treatment policy
- ☐ Shared care agreement with specialist centre
- ☐ Play support
- ☐ Written information (manual or user guide) giving instructions for use of all equipment supplied
- ☐ Written information on advance care planning where appropriate
- ☐ Arrangements to provide feedback
- ☐ None

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

☐ *LTV Centre ☐ Other

2. If answered "*LTV Centre" to [1] then:

Where is routine outpatient review for LTV patients <18 years old provided? (Please tick all that apply)

☐ Outpatient clinic ☐ Within ward environment ☐ Home assessment
☐ Unknown

Please specify any additional options here...

3. If answered "*LTV Centre" to [1] then:

How frequently are CLINICALLY STABLE LTV outpatients offered outpatient review?

☐ At least annually ☐ At least every six months ☐ At least every three months
☐ At least monthly ☐ Unknown

If not listed above, please specify here...

4. If answered "*LTV Centre" to [1] then:

How do CLINICALLY UNSTABLE LTV patients <18 years old access clinical review? (Please tick all that apply)

☐ Outpatient clinic ☐ Within ward environment
☐ Home assessment ☐ Defined urgent care pathway
☐ Emergency department attendance ☐ Direct ward admission
☐ Emergency call to GP ☐ Unknown

Please specify any additional options here...

5. If answered "*LTV Centre" to [1] then:

Please specify the number of outpatient SPACES per week for review of ventilator patients <18 years old?

If none, please use 0

spaces ☐ Unknown

6. If answered "*LTV Centre" to [1] then:

What is the approximate length of an outpatient appointment (minutes) for patients <18 years old?

☐ 15-30 minutes ☐ 30-45 minutes ☐ 45-60 minutes ☐ >60 minutes
☐ Unknown

If not listed above, please specify here...

7. If answered "*LTV Centre" to [1] then:

How often are clinical assessments included in outpatient assessments of LTV patients <18 years old?

- ☐ Offered routinely ☐ Available when required ☐ Not available
☐ Unknown

If not listed above, please specify here...

8. If answered "*LTV Centre" to [1] then:

How often is blood gas analysis included in outpatient assessments of LTV patients <18 years old?

- ☐ Offered routinely ☐ Available when required ☐ Not available
☐ Unknown

If not listed above, please specify here...

9. If answered "*LTV Centre" to [1] then:

How often is overnight oximetry included in outpatient assessments of LTV patients <18 years old?

- ☐ Offered routinely ☐ Available when required ☐ Not available
☐ Unknown

If not listed above, please specify here...

10. If answered "*LTV Centre" to [1] then:

How often is overnight polysomnography included in outpatient assessments of LTV patients <18 years old?

- ☐ Offered routinely ☐ Available when required ☐ Not available
☐ Unknown

If not listed above, please specify here...

11. If answered "*LTV Centre" to [1] then:

How often is pulmonary function testing included in outpatient assessments of LTV patients <18 years old?

- ☐ Offered routinely ☐ Available when required ☐ Not available
☐ Unknown

If not listed above, please specify here...

12. If answered "*LTV Centre" to [1] then:

How often is oxycapnography included in outpatient assessments of LTV patients <18 years old?

- ☐ Offered routinely ☐ Available when required ☐ Not available
☐ Unknown

If not listed above, please specify here...

G. INPATIENT CARE

1. Does this hospital admit patients <18 years old who are receiving LTV?

☐ Yes

☐ No

☐ Unknown

2. If answered "Yes" to [1] then:

Which of the following ward areas are long term tracheostomy-ventilated patients <18 years old admitted to? (Please tick all that apply)

☐ Adult (General) Critical Care unit

☐ Paediatric Critical Care unit

☐ Neonatal intensive care

☐ Adult high dependency unit

☐ Paediatric high dependency unit

☐ Specialist ventilator ward

☐ Specialist LTV unit

☐ Paediatric respiratory ward

☐ Adult respiratory ward

☐ Adult acute medical / general ward

☐ Paediatric acute medical / general ward

☐ Unknown

Please specify any additional options here...

3. If answered "Yes" to [1] then:

Which of the following ward areas are long term non-invasively ventilated patients <18 years old admitted to? (Please tick all that apply)

☐ Adult (General) Critical Care unit

☐ Paediatric Critical Care unit

☐ Neonatal intensive care

☐ Adult high dependency unit

☐ Paediatric high dependency unit

☐ Specialist ventilator ward

☐ Specialist LTV unit

☐ Paediatric respiratory ward

☐ Adult respiratory ward

☐ Adult acute medical / general ward

☐ Paediatric acute medical / general ward

☐ Unknown

Please specify any additional options here...

4. If answered "Yes" to [1] then:

Did this hospital at any point lack sufficient capacity to admit LTV patients <18 years old between April 1st 2016 and March 31st 2018?

☐ Yes

☐ No

☐ Unknown

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

☐ *LTV Centre ☐ Other

2a. If answered "*LTV Centre" to [1] then:

Is there an identified medical lead clinician for LTV patients <18 years old in this hospital?

☐ Yes ☐ No ☐ Unknown

2b. If answered "*LTV Centre" to [1] and "Yes" to [2a] then:

If YES, how much time is allocated in their job plan for the lead role per week?

If none, please use 0

Hours ☐ Unknown

3a. If answered "*LTV Centre" to [1] then:

Is there an identified non-medical lead in this hospital for LTV patients <18 years old?

☐ Yes ☐ No ☐ Unknown

3b. If answered "*LTV Centre" to [1] and "Yes" to [3a] then:

If YES, what specialty clinician is this?

☐ Nursing ☐ Physiotherapy ☐ Unknown

If not listed above, please specify here...

4. If answered "*LTV Centre" to [1] then:

Which of the following specialties does your LTV service have? (Please tick all that apply)

- ☐ Medical: consultant
- ☐ Medical: non-consultant
- ☐ Nursing: specialist nurse (Agenda for Change band 7 or above)
- ☐ Nursing: (Agenda for Change band 5 and 6)
- ☐ Physiotherapist
- ☐ Occupational therapist
- ☐ Psychologist/psychological support
- ☐ Speech and Language Therapist
- ☐ Dietician
- ☐ Unknown
- ☐ None

Please specify any additional options here...

5a. If answered "*LTV Centre" to [1] then:

How is physiotherapy provided for acute LTV inpatients <18 years old in this hospital? (Please tick all that apply)

- ☐ Dedicated LTV physiotherapist
- ☐ General physiotherapy service
- ☐ Unknown
- ☐ Respiratory physiotherapy service
- ☐ Physiotherapy not provided
- ☐ Other Physiotherapy

**5b. If answered "*LTV Centre" to [1] and "Other Physiotherapy" to [5a] then:
If OTHER PHYSIOTHERAPY, please specify:**

**6. If answered "*LTV Centre" to [1] then:
Please specify the number of hours per day physiotherapy cover is provided for LTV
patients <18 years old, Monday to Friday?**

Hours per day

☐ Unknown

**7. If answered "*LTV Centre" to [1] then:
Please specify the number of hours per day physiotherapy cover is provided for LTV
patients <18 years old on Saturday?**

Hours per day

☐ Unknown

**8. If answered "*LTV Centre" to [1] then:
Please specify the number of hours per day physiotherapy cover is provided for LTV
patients <18 years old on Sunday?**

Hours per day

☐ Unknown

I. DISCHARGE PLANNING

1. Does this hospital admit patients <18 years old who are receiving LTV?

- ☐ Yes ☐ No ☐ Unknown

2. If answered "Yes" to [1] then:

Does this hospital provide care for tracheostomy ventilated patients <18 years old?

- ☐ Yes ☐ No ☐ Unknown

3a. If answered "Yes" to [2] and "Yes" to [1] then:

Which of the following have caused problems with discharge for patients <18 years old who are long-term tracheostomy ventilated? (Please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Equipment - availability | <input type="checkbox"/> Equipment - funding |
| <input type="checkbox"/> Carers/staffing - availability/numbers | <input type="checkbox"/> Carers/staffing - training |
| <input type="checkbox"/> Carers/staffing - funding | <input type="checkbox"/> House adaptations |
| <input type="checkbox"/> Family carers - training | <input type="checkbox"/> None |

3b. If answered "Yes" to [2] and "Yes" to [1] then:

Please expand on your answers regarding discharging long-term tracheostomy ventilated patients:

If none, please leave blank

4. If answered "Yes" to [1] then:

Does this hospital provide care for non-invasively ventilated patients <18 years old?

- ☐ Yes ☐ No ☐ Unknown

5a. If answered "Yes" to [1] and "Yes" to [4] then:

Which of the following have caused problems with discharge for patients <18 years old who are long-term non-invasively ventilated? (Please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Equipment - availability | <input type="checkbox"/> Equipment - funding |
| <input type="checkbox"/> Carers/staffing - availability/numbers | <input type="checkbox"/> Carers/staffing - training |
| <input type="checkbox"/> Carers/staffing - funding | <input type="checkbox"/> Housing adaptations |
| <input type="checkbox"/> Family carers - training | <input type="checkbox"/> None |

5b. If answered "Yes" to [4] and "Yes" to [1] then:

Please expand on your answers regarding discharging long-term non-invasively ventilated patients:

If none, please leave blank

1. Is community LTV care provided by this hospital/organisation for patients <18 years old?

☐ Yes ☐ No ☐ Unknown

2. If answered "Yes" to [1] then:

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...

3. If answered "Yes" to [1] then:

Which of the following are available in the location where community care is delivered during normal working hours (Monday to Friday, 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...

4. If answered "Yes" to [1] then:

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...

5. If answered "Yes" to [1] then:

Who takes responsibility for the maintenance of ventilation equipment?

☐ Community service ☐ Hospital service ☐ Private provider ☐ Unknown

If not listed above, please specify here...

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

- ☐ *LTV Centre ☐ Other

2a. If answered "*LTV Centre" to [1] then:

Does this hospital run a training programme for delivery of LTV?

- ☐ Yes ☐ No ☐ Unknown

2b. If answered "*LTV Centre" to [1] and "Yes" to [2a] then:

If YES, does this include:

- ☐ NIV ☐ Tracheostomy ventilation
☐ Both NIV and tracheostomy ventilation ☐ Unknown

3a. If answered "*LTV Centre" to [1] then:

Does this service have a competency assessment for the care of LTV patients <18 years old?

- ☐ Yes ☐ No ☐ Unknown

3b. If answered "*LTV Centre" to [1] and "Yes" to [3a] then:

If YES, for who are competency assessments routinely performed within this LTV service? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Family/Parent Carers | <input type="checkbox"/> Physiotherapists |
| <input type="checkbox"/> Nurses | <input type="checkbox"/> Healthcare assistants - Hospital |
| <input type="checkbox"/> Healthcare assistants - Community | <input type="checkbox"/> Doctors |
| <input type="checkbox"/> Unknown | |

3c. If answered "*LTV Centre" to [1] and "Family/Parent Carers" to [3b] then:

If FAMILY/PARENT CARERS which of the following competencies (when relevant) are assessed routinely within this LTV service? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Ventilation | <input type="checkbox"/> Resuscitation |
| <input type="checkbox"/> Child safeguarding | <input type="checkbox"/> Infection control / disposal of clinical waste |
| <input type="checkbox"/> Tracheostomy care | <input type="checkbox"/> Oxygen administration via a ventilator |
| <input type="checkbox"/> Humidification | <input type="checkbox"/> Saturation monitoring |
| <input type="checkbox"/> Nasogastric / gastrostomy feeding | <input type="checkbox"/> Unknown |

3d. If answered "*LTV Centre" to [1] and "Physiotherapists" to [3b] then:

If PHYSIOTHERAPISTS which of the following competencies (when relevant) are assessed routinely within this LTV service? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Ventilation | <input type="checkbox"/> Resuscitation |
| <input type="checkbox"/> Child safeguarding | <input type="checkbox"/> Infection control / disposal of clinical waste |
| <input type="checkbox"/> Tracheostomy care | <input type="checkbox"/> Oxygen administration via a ventilator |
| <input type="checkbox"/> Humidification | <input type="checkbox"/> Saturation monitoring |
| <input type="checkbox"/> Nasogastric / gastrostomy feeding | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> NA | |

3e. If answered "*LTV Centre" to [1] and "Nurses" to [3b] then:

If NURSES, which of the following competencies (when relevant) are assessed routinely within this LTV service? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Ventilation | <input type="checkbox"/> Resuscitation |
| <input type="checkbox"/> Child safeguarding | <input type="checkbox"/> Infection control / disposal of clinical waste |
| <input type="checkbox"/> Tracheostomy care | <input type="checkbox"/> Oxygen administration via a ventilator |
| <input type="checkbox"/> Humidification | <input type="checkbox"/> Saturation monitoring |
| <input type="checkbox"/> Nasogastric / gastrostomy feeding | <input type="checkbox"/> Unknown |

**3f. If answered "*LTV Centre" to [1] and "Healthcare assistants - Hospital" to [3b] then:
If HEALTHCARE ASSISTANTS - HOSPITAL, which of the following competencies (when relevant) are assessed routinely within this LTV service? (Please tick all that apply)**

- | | |
|--|---|
| <input type="checkbox"/> Ventilation | <input type="checkbox"/> Resuscitation |
| <input type="checkbox"/> Child safeguarding | <input type="checkbox"/> Infection control / disposal of clinical waste |
| <input type="checkbox"/> Tracheostomy care | <input type="checkbox"/> Oxygen administration via a ventilator |
| <input type="checkbox"/> Humidification | <input type="checkbox"/> Saturation monitoring |
| <input type="checkbox"/> Nasogastric / gastrostomy feeding | <input type="checkbox"/> Unknown |

**3g. If answered "*LTV Centre" to [1] and "Healthcare assistants - Community" to [3b] then:
If HEALTHCARE ASSISTANTS - COMMUNITY, which of the following competencies (when relevant) are assessed routinely within this LTV service? (Please tick all that apply)**

- | | |
|--|---|
| <input type="checkbox"/> Ventilation | <input type="checkbox"/> Resuscitation |
| <input type="checkbox"/> Child safeguarding | <input type="checkbox"/> Infection control / disposal of clinical waste |
| <input type="checkbox"/> Tracheostomy care | <input type="checkbox"/> Oxygen administration via a ventilator |
| <input type="checkbox"/> Humidification | <input type="checkbox"/> Saturation monitoring |
| <input type="checkbox"/> Nasogastric / gastrostomy feeding | <input type="checkbox"/> Unknown |

**3h. If answered "*LTV Centre" to [1] and "Doctors" to [3b] then:
If DOCTORS, which of the following competencies (when relevant) are assessed routinely within this LTV service? (Please tick all that apply)**

- | | |
|--|---|
| <input type="checkbox"/> Ventilation | <input type="checkbox"/> Resuscitation |
| <input type="checkbox"/> Child safeguarding | <input type="checkbox"/> Infection control / disposal of clinical waste |
| <input type="checkbox"/> Tracheostomy care | <input type="checkbox"/> Oxygen administration via a ventilator |
| <input type="checkbox"/> Humidification | <input type="checkbox"/> Saturation monitoring |
| <input type="checkbox"/> Nasogastric / gastrostomy feeding | <input type="checkbox"/> Unknown |

4. If answered "*LTV Centre" to [1] then:

**What arrangements are in place to ensure COMMUNITY STAFF can manage LTV safely?
(Please tick all that apply)**

- | | |
|---|--|
| <input type="checkbox"/> Formal/Structured training programme | <input type="checkbox"/> Competency assessment |
| <input type="checkbox"/> Informal training | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> NA | <input type="checkbox"/> None |

Please specify any additional options here...

5. If answered "*LTV Centre" to [1] then:

**What arrangements are in place to ensure FAMILIES/CARERS can manage LTV safely?
(Please tick all that apply)**

- | | |
|---|--|
| <input type="checkbox"/> Formal/Structured training programme | <input type="checkbox"/> Competency assessment |
| <input type="checkbox"/> Informal training | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> NA | <input type="checkbox"/> None |

Please specify any additional options here...

6a. If answered "*LTV Centre" to [1] then:

Guidelines suggest that all children's carers should have their practice directly observed by a registered healthcare professional with the relevant competencies for at least one hour every two months. Does this service meet this standard?

- ☐ Yes ☐ No ☐ Unknown

**6b. If answered "*LTV Centre" to [1] and "No" to [6a] then:
If NO, please expand on your answer:**

7. If answered "*LTV Centre" to [1] then:

Do staff have access to emotional/psychological support or counselling?

- ☐ Yes - Integral to service
- ☐ Yes - other

- ☐ Yes - Via occupational health service
- ☐ No

L. EQUIPMENT

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

☐ *LTV Centre ☐ Other

2a. If answered "*LTV Centre" to [1] then:

Does this service have an equipment policy for LTV?

☐ Yes ☐ No ☐ Unknown

2b. If answered "Yes" to [2a] and "*LTV Centre" to [1] then:

If YES, which of the following responsibilities does this cover? (Please tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Setting up equipment | <input type="checkbox"/> Maintenance and servicing of equipment |
| <input type="checkbox"/> Emergency replacements | <input type="checkbox"/> Replacement of breakages |
| <input type="checkbox"/> Emergency contact details | <input type="checkbox"/> Return of equipment when no longer needed |
| <input type="checkbox"/> Remote assistance with Trouble shooting | <input type="checkbox"/> Unknown |

Please specify any additional options here...

3a. If answered "*LTV Centre" to [1] then:

Are there any aspects of equipment provision that could be improved in your service?

☐ Yes ☐ No ☐ Unknown

3b. If answered "Yes" to [3a] and "*LTV Centre" to [1] then:

If YES, please give details:

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

☐ *LTV Centre ☐ Other

2. If answered "*LTV Centre" to [1] then:

Does this service keep a register of long-term ventilation equipment in use by LTV patients <18 years old?

☐ Yes ☐ No ☐ Unknown

3. If answered "*LTV Centre" to [1] then:

Please specify the number of ventilator models used by this LTV service?

☐ Unknown

4a. If answered "*LTV Centre" to [1] then:

How many manufacturers does this LTV service source ventilators from?

☐ Unknown

4b. If answered "*LTV Centre" to [1] then:

If more than one manufacturer, please explain the reasons for this:

5a. If answered "*LTV Centre" to [1] then:

Does this service have an equipment service/maintenance contract for all ventilator equipment?

☐ Yes ☐ No ☐ Unknown

5b. If answered "No" to [5a] and "*LTV Centre" to [1] then:

If NO, please describe local servicing arrangements:

6. If answered "*LTV Centre" to [1] then:

Which of the following are provided for *High (level 1) ventilator dependent LTV patients <18 years old by this service? (Please tick all that apply)

**Please see definitions*

- ☐ Two ventilators including internal and external battery backup
- ☐ Two oxygen saturation monitor or one oxygen saturation monitor and robust arrangements for replace
- ☐ Hand-held saturation monitor
- ☐ Self-inflating bag
- ☐ Two sets of suction equipment
- ☐ Two sets of appropriate humidification equipment
- ☐ Access to a mobile phone and to a land line in the home (or back up mobile)
- ☐ Call system
- ☐ Carbon dioxide monitoring equipment
- ☐ Access to a replacement ventilator within 24 hours
- ☐ Cough assist when required
- ☐ Unknown
- ☐ None
- ☐ NA

Please specify any additional options here...

7. If answered "*LTV Centre" to [1] then:

Which of the following are provided for *Severe (level 2) ventilator dependent LTV patients ≤18 years old by this service? (Please tick all that apply)

**Please see definitions*

- ☐ Two ventilators including internal and external battery backup
- ☐ Two oxygen saturation monitor or one oxygen saturation monitor and robust arrangements for replace
- ☐ Hand-held saturation monitor
- ☐ Self-inflating bag
- ☐ Two sets of suction equipment
- ☐ Two sets of appropriate humidification equipment
- ☐ Access to a mobile phone and to a land line in the home (or back up mobile)
- ☐ Call system
- ☐ Carbon dioxide monitoring equipment
- ☐ Access to a replacement ventilator within 24 hours
- ☐ Cough assist when required
- ☐ Unknown
- ☐ None
- ☐ NA

Please specify any additional options here...

8. If answered "*LTV Centre" to [1] then:

Which of the following are provided for *Priority (level 3) ventilator dependency LTV patients <18 years old by this service? (Please tick all that apply)

**Please see definitions*

- ☐ Two ventilators including internal and external battery backup
- ☐ Two oxygen saturation monitor or one oxygen saturation monitor and robust arrangements for replace
- ☐ Hand-held saturation monitor
- ☐ Self-inflating bag
- ☐ Two sets of suction equipment
- ☐ Two sets of appropriate humidification equipment
- ☐ Access to a mobile phone and to a land line in the home (or back up mobile)
- ☐ Call system
- ☐ Carbon dioxide monitoring equipment
- ☐ Access to a replacement ventilator within 24 hours
- ☐ Cough assist when required
- ☐ Unknown
- ☐ None
- ☐ NA

Please specify any additional options here...

9a. If answered "*LTV Centre" to [1] then:

Has this service had problems accessing appropriate equipment for LTV patients <18 years old?

- ☐ Yes ☐ No ☐ Unknown

9b. If answered "Yes" to [9a] and "*LTV Centre" to [1] then:

If YES, please give details:

1. Does this hospital admit patients <18 years old who are receiving LTV?

☐ Yes ☐ No ☐ Unknown

2. If answered "Yes" to [1] then:

Does this hospital provide care for tracheostomy-ventilated patients <18 years old?

☐ Yes ☐ No

3. If answered "Yes" to [2] and "Yes" to [1] then:

Where are routine (after first) tracheostomy tube changes undertaken? (Please tick all that apply)

☐ At home ☐ Outpatients ☐ Inpatient ward ☐ Critical Care Unit
☐ Unknown

Please specify any additional options here...

4. If answered "Yes" to [2] and "Yes" to [1] then:

Does this hospital have continuous (24/7) access to a consultant led ENT service?

☐ Yes ☐ No ☐ Unknown

5. If answered "Yes" to [2] and "Yes" to [1] then:

Are arrangements in place for the same surgical team to perform tracheostomy insertion in all patients <18 years old requiring LTV?

☐ Yes ☐ No ☐ NA (LTV not initiated)
☐ Unknown

6a. If answered "Yes" to [2] and "Yes" to [1] then:

Does this service use a standard type/model of tracheostomy tubes for all patients <18 years old?

☐ Yes ☐ No ☐ Unknown

6b. If answered "Yes" to [2] and "No" to [6a] and "Yes" to [1] then:

If NO, please expand:

O. NON-INVASIVE VENTILATION

1. Does this hospital admit patients <18 years old who are receiving LTV?

☐ Yes

☐ No

☐ Unknown

2. If answered "Yes" to [1] then:

Does this hospital provide care for non-invasively ventilated patients <18 years old?

☐ Yes

☐ No

3a. If answered "Yes" to [2] and "Yes" to [1] then:

Does this service offer a choice of mask TYPE for provision of LTV?

☐ Yes

☐ No

☐ Unknown

3b. If answered "Yes" to [2] and "Yes" to [3a] and "Yes" to [1] then:

If YES, how many different TYPES of masks are offered?

☐ Unknown

4. If answered "Yes" to [2] and "Yes" to [1] then:

How many different mask SIZES does this service offer for LTV?

☐ Unknown

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

☐ *LTV Centre ☐ Other

2a. If answered "*LTV Centre" to [1] then:

Does this service have a guideline for transition of paediatric LTV patients to adult services?

☐ Yes ☐ No ☐ Unknown

2b. If answered "Yes" to [2a] and "*LTV Centre" to [1] then:

If YES, does this guidance specify an age at which transition must be considered?

☐ Yes ☐ No ☐ Unknown

2c. If answered "Yes" to [2a] and "Yes" to [2b] and "*LTV Centre" to [1] then:

If YES, at what age (years) does transition planning begin?

years ☐ Unknown

3a. If answered "*LTV Centre" to [1] then:

Does this service have a named executive lead for transition?

☐ Yes ☐ No ☐ Unknown

3b. If answered "Yes" to [3a] and "*LTV Centre" to [1] then:

If YES, what is their job title?

☐ Medical Director ☐ Nursing Director ☐ Unknown

If not listed above, please specify here...

4. If answered "*LTV Centre" to [1] then:

Does this service have a named clinician for transition?

☐ Yes ☐ No ☐ Unknown

5. If answered "*LTV Centre" to [1] then:

Does this service provide a single practitioner ('named worker') to co-ordinate transition of care for LTV patients?

☐ Yes ☐ No ☐ Unknown

6. If answered "*LTV Centre" to [1] then:

Do local transition arrangements for patients on LTV include involvement of the GP?

☐ Yes ☐ No ☐ Unknown

7. If answered "*LTV Centre" to [1] then:

Are joint appointments with the paediatric and adult LTV services available for patients who transition between these services?

☐ Yes ☐ No ☐ Unknown

8. If answered "*LTV Centre" to [1] then:

Are patients given written notes/documentation describing the changed arrangements on transfer?

☐ Yes ☐ No ☐ Unknown

9. If answered "*LTV Centre" to [1] then:

Does the service hold an MDT meeting to discuss young people <18 years old in transition?

☐ Yes

☐ No

☐ Unknown

10a.If answered "*LTV Centre" to [1] then:

Are adult and paediatric services co-located (e.g. on the same hospital site)?

☐ Yes

☐ No

☐ Unknown

10b.If answered "No" to [10a] and "*LTV Centre" to [1] then:

If NO, please give details:

11. If answered "*LTV Centre" to [1] then:

After transition, are arrangements in place to ensure that patients are seen by the same healthcare practitioner for at least the first two appointments?

☐ Yes

☐ No

☐ Unknown

12a.If answered "*LTV Centre" to [1] then:

Following transition, is there a difference in the type of equipment available for patients?

☐ Yes

☐ No

☐ Unknown

12b.If answered "Yes" to [12a] and "*LTV Centre" to [1] then:

If YES, please give details:

13a.If answered "*LTV Centre" to [1] then:

Following transition, is there a difference in the clinical support available for patients?

☐ Yes

☐ No

☐ Unknown

**13b.If answered "Yes" to [13a] and "*LTV Centre" to [1] then:
If YES, please give details:**

**14a.If answered "*LTV Centre" to [1] then:
Are there any aspects of transition that could be improved in your service?**

☐ Yes ☐ No ☐ Unknown

**14b.If answered "Yes" to [14a] and "*LTV Centre" to [1] then:
If YES, please give details:**

Q. COMMISSIONING ARRANGEMENTS

1. What type of centre is this?

**LTV centre is defined as one which provides this patient with the normal decision making, support and review of their ventilatory care*

☐ *LTV Centre ☐ Other

2. If answered "*LTV Centre" to [1] then:

Are formal commissioning arrangements in place for this LTV service?

☐ Yes ☐ No ☐ Unknown

3. If answered "*LTV Centre" to [1] then:

Which of the following are commissioned for LTV patients <18 years old? (Please tick all that apply)

☐ Tertiary children's LTV service ☐ Step down service
☐ Short break/respite service ☐ Home support service
☐ Unknown

Please specify any additional options here...

4. If answered "*LTV Centre" to [1] then:

Do local commissioners have formal arrangements in place to monitor the quality of LTV services for patients <18 years old?

☐ Yes ☐ No ☐ Unknown

5. If answered "*LTV Centre" to [1] then:

Where problems are identified with LTV service provision, are arrangements in place to address these through the monitoring process?

☐ Yes ☐ No ☐ Unknown ☐ NA

6a. If answered "*LTV Centre" to [1] then:

Are there any aspects of commissioning that could be improved?

☐ Yes ☐ No ☐ Unknown

6b. If answered "Yes" to [6a] and "*LTV Centre" to [1] then:

If YES, please give details:

Many thanks for taking the time to complete this questionnaire