

# Long-term Ventilation Organisational Questionnaire: Adult 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.

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### **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)'.

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### **Who should complete this questionnaire?**

This form should be completed by organisations who provide care for  $\geq 18$  years old. The person completing the form should have knowledge of this hospital/service's organisation of care.

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### **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.

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### **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 ≥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

### 8. Does this hospital have an emergency department?

- Yes       No       Unknown       NA

### 9. Does the hospital have an emergency admission unit?

- Yes       No       Unknown       NA

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

- |  |                                  |
|--|----------------------------------|
| <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"/> Adult LTV beds                                    | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> NA  | <input type="checkbox"/> None    |

**11. 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...

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

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

*\*Please see definitions*

- |   |   |   |                               |
|---|---|---|-------------------------------|
| <input type="checkbox"/> High (level 1) | <input type="checkbox"/> Severe (level 2) | <input type="checkbox"/> Priority (level 3) | <input type="checkbox"/> None |
|---|---|---|-------------------------------|

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

**In terms of LTV patients  $\geq 18$  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

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

- Yes  No  Unknown

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

- Yes  No  Unknown

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

- Yes  No  Unknown  NA

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

- Yes  No  Unknown

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

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 for patients  $\geq 18$  years old?**

- Yes       No       Unknown

**2b. If answered "Yes" to [2a] and "\*LTV Centre" to [1] 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  $\geq 18$  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
- 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       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 ≥18 years old 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)**

- |  |  |
|--|--|
| <input type="checkbox"/> Outpatient clinic               | <input type="checkbox"/> Within ward environment     |
| <input type="checkbox"/> Home assessment                 | <input type="checkbox"/> Defined urgent care pathway |
| <input type="checkbox"/> Emergency department attendance | <input type="checkbox"/> Direct ward admission       |
| <input type="checkbox"/> Emergency call to GP            | <input type="checkbox"/> 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?**

- spaces       Unknown

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

**What is the approximate length of an outpatient appointment (minutes)?**

- 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  $\geq 18$  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  $\geq 18$  years old admitted to? (Please tick all that apply)**

- |  |   |
|--|---|
| <input type="checkbox"/> Adult (General) Critical Care unit      | <input type="checkbox"/> Paediatric Critical Care unit      |
| <input type="checkbox"/> Neonatal intensive care                 | <input type="checkbox"/> Adult high dependency unit         |
| <input type="checkbox"/> Paediatric high dependency unit         | <input type="checkbox"/> Specialist ventilator ward         |
| <input type="checkbox"/> Specialist LTV unit                     | <input type="checkbox"/> Paediatric respiratory ward        |
| <input type="checkbox"/> Adult respiratory ward                  | <input type="checkbox"/> Adult acute medical / general ward |
| <input type="checkbox"/> Paediatric acute medical / general ward | <input type="checkbox"/> 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  $\geq 18$  years old admitted to? (Please tick all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> Adult (General) Critical Care unit | <input type="checkbox"/> Paediatric Critical Care unit           |
| <input type="checkbox"/> Neonatal intensive care            | <input type="checkbox"/> Paediatric high dependency unit         |
| <input type="checkbox"/> Specialist ventilator ward         | <input type="checkbox"/> Specialist LTV unit                     |
| <input type="checkbox"/> Paediatric respiratory ward        | <input type="checkbox"/> Adult respiratory ward                  |
| <input type="checkbox"/> Adult acute medical / general ward | <input type="checkbox"/> Paediatric acute medical / general ward |
| <input type="checkbox"/> Adult high dependency unit         | <input type="checkbox"/> 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  $\geq 18$  years old between April 1st 2016 and March 31st 2018?**

- Yes                       No                       Unknown

**1. What type of centre is this?**

- \*LTV Centre       Other

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

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

- Yes       No       Unknown

**2b. If answered "Yes" to [2a] and "\*LTV Centre" to [1] 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 "Yes" to [3a] and "\*LTV Centre" to [1] 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 "Other Physiotherapy" to [5a] and "\*LTV Centre" to [1] then:  
If OTHER PHYSIOTHERAPY, please specify:**

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

Hours per day

Unknown

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

Hours per day

Unknown

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

Hours per day

Unknown

I. DISCHARGE PLANNING

**1. Does this hospital admit patients  $\geq 18$  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  $\geq 18$  years old?**

- Yes                       No                       Unknown

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

**Which of the following have caused problems with discharge for patients  $\geq 18$  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 [1] and "Yes" to [2] 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  $\geq 18$  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  $\geq 18$  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 [1] and "Yes" to [4] 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  $\geq 18$  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  $\geq 18$  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       Other

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

**Does this hospital run a training programme for delivery of LTV for patients  $\geq 18$  years old?**

- Yes       No       Unknown

**2b. If answered "Yes" to [2a] and "\*LTV Centre" to [1] 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  $\geq 18$  years old?**

- Yes       No       Unknown

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

**If FAMILY/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  |

Please specify any additional options here...

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

**3e. If answered "Nurses" to [3b] and "\*LTV Centre" to [1] 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 "Healthcare assistants - Hospital" to [3b] and "\*LTV Centre" to [1] 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 "Healthcare assistants - Community" to [3b] and "\*LTV Centre" to [1] 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 "Doctors" to [3b] and "\*LTV Centre" to [1] 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  |

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**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...

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**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...

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**6. If answered "\*LTV Centre" to [1] then: Do staff have access to emotional/psychological support or counselling?**

- |   |   |
|---|---|
| <input type="radio"/> Yes - Integral to service | <input type="radio"/> Yes - via occupational health service |
| <input type="radio"/> Yes - other               | <input type="radio"/> No                                    |
| <input type="radio"/> Unknown                   |   |

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  $\geq 18$  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:**

N. TRACHEOSTOMY VENTILATION

**1. Does this hospital admit patients  $\geq 18$  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  $\geq 18$  years old?**

- Yes                       No

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

**Where are routine (after first) tracheostomy tube changes undertaken for patients  $\geq 18$  years old? (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 [1] and "Yes" to [2] then:**

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

- Yes                       No                       Unknown

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

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

- Yes                       No                       NA (LTV not initiated)  
 Unknown

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

**Does this service use a standard type/model of tracheostomy tubes for all patients  $\geq 18$  years old?**

- Yes                       No                       Unknown

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

**If NO, please expand:**

O. NON-INVASIVE VENTILATION

**1. Does this hospital admit patients  $\geq 18$  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  $\geq 18$  years old?**

Yes

No

---

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

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

Yes

No

Unknown

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

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

Types

Unknown

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

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

Sizes

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  $\geq 18$  years old in transition?**

Yes

No

Unknown

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**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:**

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**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

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**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:**

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**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  $\geq 18$  years old? (Please tick all that apply)**

- Tertiary adult LTV service       Step down service       Short break/respice service  
 Home support service       Unknown

**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  $\geq 18$  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**