

Long-term ventilation: Admission to hospital 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?

For completion by the clinician in charge of the most recent acute admission during the study period (1st April 2016 – 31st March 2018).

We recognise that patients may be admitted/transferred to a number of different locations of care. This questionnaire has been designed to collect data for admissions to both specialist (LTV centres) and non-specialist (non-LTV centres) hospitals. If a patient was transferred from a non-specialist hospital to a specialist hospital, this questionnaire will need to be completed for both locations, and each clinician will be sent the questionnaire to complete for the different time points.

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. CLINICIAN DETAILS AND STRUCTURED COMMENTARY

1a. Professional group:

1b. Grade:

1c. Specialty:

1d. 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.

C. HOSPITAL DETAILS

1a. What type of centre is this hospital?

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

- Non LTV* centre LTV* centre Unknown

1b. Please indicate what type of hospital this is:

- DGH <500 beds DGH ≥500 beds
 Specialist Paediatric Tertiary Centre University Teaching Hospital
 Independent Hospital Unable to answer

If not listed above, please specify here...

1c. How far is this hospital from the patient's normal residence?

- <25 miles 25-50 miles 51-100 miles >100 miles
 Unknown

1d. Is this hospital the lead centre for LTV provided for this patient?

- Yes No Unknown

1e. If answered "No" to [1d] then:

If NO (the patient was not admitted to their usual place of LTV care), please provide details of the TRUST/HEALTH BOARD which provides lead services.

1f. If answered "No" to [1d] then:

If NO (the patient was not admitted to their usual place of LTV care), please provide details of the HOSPITAL which provides lead services:

1g. If answered "No" to [1d] then:

If NO, how far is the lead LTV centre from the patient's normal residency?

- <25 miles 25-50 miles 51-100 miles >100 miles
 Unknown

1h. If answered "No" to [1d] then:

If NO, are you part of the team who clinically manage the long-term care of the patient?

- Yes No Unknown

1i. If answered "No" to [1d] then:

If NO, are you this patient's lead clinician for LTV in this hospital?

- Yes No Unknown

1j. If answered "No" to [1i] then:

If NO, does the patient have a named lead clinician for LTV in this hospital?

- Yes No Unknown

D. PATIENT SPECIFIC DETAILS AND BACKGROUND

1a. Was the patient aged ≥ 2 years at the time of admission?

- Yes No Unknown

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

If YES, please specify the patients age in years:

 Years

- Unknown

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

If NO, please specify the age in months:

 Months

- Unknown

2. Sex:

- Male Female Unknown

3. Weight:

 kg

- Unknown

4a. Had the patient been receiving ventilation for ≥ 2 years at the time of admission?

- Yes No Unknown

4b. If answered "Yes" to [4a] then:

If YES, please specify the length of time on ventilation overall in years?

 Years

- Unknown

4c. If answered "No" to [4a] then:

If NO, please specify the length of time on ventilation overall in months?

 Months

- Unknown

5. Prior to admission, what type of LTV was the patient normally receiving?

- Invasive (Via. Tracheostomy) Non-invasive (Via. mask, prongs)
 Unknown

6a. How was ventilation delivered before admission to this hospital?

- Endotracheal tube/tracheostomy Non-invasive ventilation
 Unknown

6b. What type of ventilation (if applicable) was delivered?

- Continuous Positive Airway Pressure (CPAP) Bi-level Positive Airway Pressure (BIPAP)
 Invasive positive pressure ventilation Not applicable
 Unknown

If not listed above, please specify here...

**6c. If answered "Invasive (Via. Tracheostomy)" to [5] then:
If INVASIVE VENTILATION VIA. A TRACHEOSTOMY, what size was the tube? (mm internal diameter) (Please specify if cuffed or uncuffed)**

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

- | | |
|--|--|
| <input type="checkbox"/> Respiratory muscle weakness | <input type="checkbox"/> Central drive |
| <input type="checkbox"/> Upper airway obstruction | <input type="checkbox"/> Skeletal deformity e.g. Scoliosis |
| <input type="checkbox"/> Spinal cord injury | <input type="checkbox"/> Obesity hypoventilation |
| <input type="checkbox"/> Neurodisability | <input type="checkbox"/> Unknown |

Please specify any additional options here...

8. Did this patient have other significant co-morbidities/associated problems? (Please tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Poor cough | <input type="checkbox"/> Unsafe swallow |
| <input type="checkbox"/> Nutritional problems | <input type="checkbox"/> Congenital abnormalities of Head/Neck |
| <input type="checkbox"/> None | <input type="checkbox"/> Unknown |

Please specify any additional options here...

9a. Was the patient dependent on other equipment/technologies?

- Yes No Unknown

**9b. If answered "Yes" to [9a] then:
If YES, please specify:**

- Artificial feeding - tube
- Artificial feeding - PEG
- Wheelchair
- Devices to assist with communication, hearing or vision
- Cough assist devices
- Unknown

Please specify any additional options here...

1a. Date of arrival:

1b. Time of arrival:*Please use 24hr clock*

2a. What was the location of care prior to admission to this hospital?

- Home Hospice/Respite care LTV unit
 Another hospital Unknown

If not listed above, please specify here...

2b. If answered "Another hospital" to [2a] then:**If ANOTHER HOSPITAL, please specify the duration of care in the previous hospital prior to transfer:***Please round up to nearest half day*
 Days
 Unknown**2c. If answered "Another hospital" to [2a] then:****If ANOTHER HOSPITAL, please specify the name of the TRUST/HEALTH BOARD:**

2d. If answered "Another hospital" to [2a] then:**If ANOTHER HOSPITAL, please specify the name of the HOSPITAL:**

3a. How was this patient transported to this hospital?

- Ambulance (normal 999 service)
 Family car
 Dedicated ambulance transfer service (including medical/nursing support)
 Unknown

If not listed above, please specify here...

3b. Were there any problems during transportation to this hospital?

- Yes No Unknown

3c. If answered "Yes" to [3b] then:**If YES what did these include? (Please tick all that apply)**

- Equipment failure
 Lack of availability of equipment
 Mask issues (fit etc.)
 Tracheostomy problems
 Humidification problems
 Changing or increasing ventilator requirements
 Problems with oxygenation (poor saturations, increased oxygen needs)
 Issues with appropriate special ambulance for safe transfer (size/equipment)
 Issues with appropriate staff competences for safe transfer
 Unknown

Please specify any additional options here...

4a. What was the date of the first assessment on arrival to this hospital?

4b. What was the time of the first assessment on arrival to this hospital?

Please use 24hr clock

5a. What was the grade of the first assessor on arrival at this hospital?

- Consultant
- Staff grade/Associate specialist
- Trainee with CCT
- Senior specialist trainee (ST3+ or equivalent)
- Junior specialist trainee (ST1&ST2 or CT equivalent)
- Basic grade (HO/FY1 or SHO/FY2 or equivalent)
- Specialist Nurse (Nurse consultant, Nurse practitioner, clinical nurse specialist)
- Senior staff nurse, enrolled nurse (EN) etc.
- 1st Level nurse, staff nurse (RGN)
- Non-registered staff (HCA etc.)
- Unknown

If not listed above, please specify here...

5b. What was the specialty of the first assessor on arrival at this hospital?

- | | |
|--|---|
| <input type="radio"/> Critical care medicine | <input type="radio"/> Paediatric intensive care |
| <input type="radio"/> Paediatrics | <input type="radio"/> Paediatric respiratory medicine |
| <input type="radio"/> Paediatric cardiology | <input type="radio"/> Paediatric neurology |
| <input type="radio"/> Accident and emergency (A&E) | <input type="radio"/> Paediatric cardiology |
| <input type="radio"/> General medicine | <input type="radio"/> Acute internal medicine |
| <input type="radio"/> Respiratory medicine | <input type="radio"/> Neurology |
| <input type="radio"/> Rehabilitation | <input type="radio"/> Palliative medicine |
| <input type="radio"/> Ear, nose and throat (ENT) | <input type="radio"/> Paediatric surgery |
| <input type="radio"/> Anaesthetics | <input type="radio"/> General surgery |
| <input type="radio"/> Other | |

6. Where was the patient first assessed on arrival?

- | | |
|--|--|
| <input type="radio"/> Emergency Department | <input type="radio"/> Admissions unit |
| <input type="radio"/> Paediatric Critical Care unit - Level 1 | <input type="radio"/> Paediatric Critical Care unit - Level 2 |
| <input type="radio"/> Paediatric Critical Care unit - Level 3 | <input type="radio"/> Adult (General) Critical Care unit - Level 2 |
| <input type="radio"/> Adult (General) Critical Care unit - Level 3 | <input type="radio"/> Neonatal unit |
| <input type="radio"/> Specialist respiratory ward | <input type="radio"/> Unknown |

If not listed above, please specify here...

7a. Did the patient have a fast track admission plan/pathway in place?

- Yes No Unknown

7b. If answered "Yes" to [7a] then:
If YES, was this followed?

- Yes No Unknown

**7c. If answered "No" to [7b] and "Yes" to [7a] then:
If NO, why not? (Please specify):**

8. If the patient had a tracheostomy did they have a tracheostomy passport?

- Yes No Unknown Not applicable

9a. Was an Emergency Health Care Plan readily available/accessible on admission?

- Yes No Unknown Not applicable

9b. If answered "Yes" to [9a] then:

If YES, was this plan one which this unit participated in planning/providing?

- Yes No Unknown

9c. If answered "Yes" to [9a] then:

If YES, did the patient/carers have a copy of this plan?

- Yes No Unknown

9d. If answered "Yes" to [9a] then:

If YES, was the patient's GP fully aware of the admission pathway/plan?

- Yes No Unknown

F. ADMISSION

1a. Please specify the date of admission to this hospital?

1b. Please specify the time of admission to this hospital?

Please use 24hr clock

2. Was the admission to this hospital:

- Planned/Scheduled (e.g. for surgery, review or respite)
 Unplanned (e.g. for emergency/urgent care)
 Unknown

3. What was the main reason for admission to this hospital?

- Acute illness Planned Surgery Urgent surgery
 Planned respiratory review Respite care Unknown

If not listed above, please specify here...

4a. At the time of admission to this hospital what was the level of dependency on LTV?

Please see definitions: <https://www.ncepod.org.uk/ltv.html>

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

4b. What was the number of hours of ventilator-free breathing per day?

Hours

- Unknown

4c. Had the level of dependency changed from the patient's stable/usual LTV pattern and prior to admission to this hospital?

- Yes No Unknown

4d. If answered "Yes" to [4c] then:

If YES, what was the previous (normal) LTV dependency?

Please see definitions: <https://www.ncepod.org.uk/ltv.html>

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

4e. Had the number of ventilator-free breathing hours changed prior to admission to this hospital?

- Yes No Unknown

4f. If answered "Yes" to [4e] then:

If YES, what was the previous number of ventilator-free hours?

Hours

- Unknown

4g. Were there any other issues relating to LTV which resulted in the patient being unstable?

- Yes No Unknown

**4h. If answered "Yes" to [4g] then:
If YES, please specify:**

5a. Were there problems with LTV apparent at admission to this hospital?

Yes No Unknown

**5b. If answered "Yes" to [5a] then:
If YES, what were these problems? (Please tick all that apply)**

- Equipment failure
- Lack of availability of equipment
- Mask issues (fit etc.)
- Tracheostomy problems
- Humidification problems
- Patient compliance
- Changing or increasing ventilator requirements
- Problems with oxygenation (poor saturations, increased oxygen needs)
- Unknown

Please specify any additional options here...

6a. Were there other contributing social or delivery of care factors which led to this hospital admission?

Yes No Unknown

**6b. If answered "Yes" to [6a] then:
If YES, what were these? (Please tick all that apply)**

- Availability of carers/breakdown of care team or leadership
- Family issues
- Lack of local respite care
- Unknown

Please specify any additional options here...

7a. Could this admission have been anticipated?

Yes No Unknown Not applicable

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

7c. Could this admission have been prevented?

- Yes No Unknown Not applicable

**7d. If answered "Yes" to [7c] then:
If YES, please give details:**

**8. If answered "Planned/Scheduled (e.g. for surgery, review or respite)" to [2] then:
If PLANNED/SCHEDULED admission, was there any difficulty in admitting the patient to hospital?**

- Yes No Unknown

9. Where was the patient first admitted to?

- | | |
|--|--|
| <input type="radio"/> Paediatric Critical Care unit - Level 1 | <input type="radio"/> Paediatric Critical Care unit - Level 2 |
| <input type="radio"/> Paediatric Critical Care unit - Level 3 | <input type="radio"/> Adult (General) Critical Care unit - Level 2 |
| <input type="radio"/> Adult (General) Critical Care unit - Level 3 | <input type="radio"/> Neonatal unit |
| <input type="radio"/> Specialist respiratory ward | <input type="radio"/> Unknown |

If not listed above, please specify here...

10a. Were there any delays in the admission process to this hospital?

- Yes No Unknown

10b.If answered "Yes" to [10a] then:

If YES, did these relate to: (please tick all that apply)

- Need for intensive resuscitation/stabilisation prior to transfer to appropriate ward/bed space
- Appropriate bed space/location
- Appropriate equipment/equipment support
- Appropriate trained staff
- Unknown

Please specify any additional options here...

11a.What was the date of the first consultant assessment following admission, in this hospital?

11b.What was the time of the first consultant assessment following admission, in this hospital?

Please use 24hr clock

11c.Is there evidence of daily consultant review documented in the case notes?

- Yes No Unknown

11d.Is there evidence of daily senior review (ST3+) documented in the case notes?

- Yes No Unknown

12a.Were there any significant problems with delivery of care during admission to this hospital?

- Yes No Unknown

12b.If answered "Yes" to [12a] then:

If YES did these relate to: (Please tick all that apply)

- Need for intensive resuscitation/stabilisation prior to transfer to appropriate ward/bed space
- Appropriate bed space/location
- Appropriate equipment/equipment support
- Appropriate trained staff (dependency and competency)
- Unknown

Please specify any additional options here...

G. PREVIOUS ADMISSIONS

If there were multiple admissions, please answer the following questions in relation to the most recent admission prior to the index admission

1. Did the patient have any acute admissions to this hospital in the 6 months prior to the acute admission?

- Yes No Unknown

2. If answered "Yes" to [1] then:
If YES, how many?

Admissions

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

- Planned/Scheduled (e.g. for surgery, review or respite)
 Unplanned (e.g. for emergency/urgent care)
 Unknown

4. If answered "Yes" to [1] then:
What was the main reason for admission?

- Acute illness
 Planned Surgery
 Urgent surgery
 Planned respiratory review
 Respite
 Changes in ventilation status (increased dependency or ineffective ventilation)
 Changing or increasing oxygen requirements
 Unknown

If not listed above, please specify here...

--

5a. If answered "Yes" to [1] then:
Did the admission include problems with the delivery of LTV?

- Yes No Unknown

5b. If answered "Yes" to [1] and "Yes" to [5a] then:
If YES, what were these problems? (Please tick all that apply)

- Equipment failure
 Lack of availability of equipment
 Mask issues (fit etc.)
 Tracheostomy problems
 Humidification problems
 Changing or increasing ventilator requirements
 Problems with oxygenation (poor saturations, increased oxygen needs)
 Unknown

Please specify any additional options here...

--

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

Were there other contributing social or delivery of care factors which led to the hospital admission?

- Yes No Unknown

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

If YES, what were these? (Please tick all that apply)

- Availability of carers/breakdown of care team or leadership
 Family issues
 Lack of local respite care
 Unknown

Please specify any additional options here...

7a. If answered "Yes" to [1] then:

Could this admission have been anticipated?

- Yes No Unknown Not applicable

7b. If answered "Yes" to [1] and "Yes" to [7a] then:

If YES, please give details:

7c. If answered "Yes" to [1] then:

Could this admission have been prevented?

- Yes No Unknown Not applicable

7d. If answered "Yes" to [1] and "Yes" to [7c] then:

If YES, please give details:

7e. If answered "Yes" to [1] and "Planned/Scheduled (e.g. for surgery, review or respite)" to [3] then:

If PLANNED/SCHEDULED admission, was there any difficulty in admitting the patient to hospital?

- Yes No Unknown

H. TRANSFERS (INCLUDES TRANSFERS WITHIN AND BETWEEN HOSPITALS)

1a. Was the patient transferred to another unit/ward in the same hospital during this admission?

- Yes No Unknown

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

If YES, what ward area were they transferred to:

- Paediatric Critical Care unit - Level 1 Paediatric Critical Care unit - Level 2
 Paediatric Critical Care unit - Level 3 Adult (General) Critical Care unit - Level 2
 Adult (General) Critical Care unit - Level 3 Neonatal unit
 Specialist respiratory ward Unknown

If not listed above, please specify here...

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

What was the reason(s) for this transfer? (Please tick all that apply)

- Escalation of care
 De-escalation of care
 Staffing competencies/ratios to meet complexity of patients needs
 Unknown

Please specify any additional options here...

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

Was there a delay in organising this transfer?

- Yes No Unknown

1e. If answered "Yes" to [1a] and "Yes" to [1d] then:

If YES, how long was this delay?

Hours Unknown

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

What was the duration of care in this location?

Days Unknown

2a. Was the patient transferred to another hospital during this admission?

- Yes No Unknown

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

What was the date of transfer

2c. If answered "Yes" to [2a] then:

What was the time of transfer

Please use 24hr clock

2d. If answered "Yes" to [2a] then:

What was the distance from patient's home/community care unit to the transfer hospital?

- <25 miles 25-50 miles 50-100 miles >100 miles
 Unknown

2e. If answered "Yes" to [2a] then:

What was the reason(s) for transfer from this hospital? (Please tick all that apply)

- Escalation of care De-escalation of care Unknown

Please specify any additional options here...

2f. If answered "Yes" to [2a] then:

Was there a significant delay in organising this transfer?

- Yes No Unknown

2g. If answered "Yes" to [2a] and "Yes" to [2f] then:

If YES, how long was this delay?

Days Unknown

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

Were there any other problems with LTV care prior to transfer?

- Yes No Unknown

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

If YES, please give further details

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

If TRANSFERRED TO ANOTHER HOSPITAL, did the patient undergo consultant review prior to discharge?

- Yes No Unknown

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

How would you rate the inter-hospital transfer?

- Good Adequate Poor Unacceptable
 Unknown

5b. If answered "Yes" to [2a] and "Good", "Adequate", "Poor" or "Unacceptable" to [5a] then:

Please give details:

I. ADVERSE EVENTS/COMPLICATIONS

1a. Did the patient have any complications or adverse events during the admission to this hospital?

- Yes No Unknown

**1b. If answered "Yes" to [1a] then:
If YES, did these relate to the delivery of LTV?**

- Yes No Unknown

**1c. If answered "Yes" to [1a] then:
If YES, what level of severity were these adverse events or complications?**

Please see definitions: <https://www.ncepod.org.uk/ltv.html>

- No patient harm Low harm Moderate harm Severe harm
 Unknown

**1d. If answered "Yes" to [1a] and "Moderate harm" or "Severe harm" to [1c] then:
If MODERATE OR SEVERE HARM occurred , please give details of incident: (please specify)**

2a. Were any other problems with LTV care identified irrespective of the cause for admission?

- Yes No Unknown

**2b. If answered "Yes" to [2a] then:
If Yes please give details**

1a. Was the admission location appropriate for the patient's severity of illness/physiological status?

- Yes No Unknown

**1b. If answered "No" to [1a] then:
If NO, why not? (Please specify):**

2a. Was the admission location appropriate for the patient's overall needs?

- Yes No Unknown

**2b. If answered "No" to [2a] then:
If NO, why not? (Please specify):**

3a. In general, was the staffing appropriate for the patient's overall needs? (Including number and skill mix)

- Yes No Unknown

**3b. If answered "No" to [3a] then:
If NO, why not?**

4a. Was the admission location appropriate for the patient's age?

- Yes No Unknown

**4b. If answered "No" to [4a] then:
If NO, why not? (Please specify):**

K. OUTCOME

1a. What was the outcome following admission to this hospital?

- Discharged alive - normal residence
- Discharged alive (non LTV centre)
- Discharged alive - other
- Died
- Discharge alive - another hospital (LTV centre)
- Discharged alive - hospice
- Still an inpatient

If not listed above, please specify here...

**1b. If answered "Discharged alive - other" to [1a] then:
If discharged alive - other, please specify:**

**2a. If answered "Died" to [1a] then:
What was the date of death?**

**2b. If answered "Died" to [1a] then:
What was the time of death?**

Please use 24hr clock

**3. If answered "Died" to [1a] then:
What were the events leading up to death? Please give details:**

**4a. If answered "Died" to [1a] then:
Was the death expected or unexpected?**

- Expected
- Unexpected
- Unknown

**4b. If answered "Died" to [1a] and "Expected" to [4a] then:
If the death was expected was a palliative care pathway in place?**

- Yes
- No
- Unknown

**4c. If answered "Died" to [1a] and "Expected" to [4a] and "Yes" to [4b] then:
If YES did this include information about what action was to be taken in terms of escalation of LTV where these was acute deterioration?**

- Yes No Unknown

4d. If answered "Died" to [1a] and "Expected" to [4a] and "Yes" to [4b] and "Yes" to [4c] then:

If YES was there a clear DNACPR guideline in place for this patient?

- Yes No Unknown
-

**5a. If answered "Died" to [1a] then:
Was the death referred to the coroner or procurator fiscal?**

- Yes No Unknown

**5b. If answered "Died" to [1a] then:
Was the death referred for other statutory external review? (e.g. CDOP, Review of patients with learning difficulties etc)**

- Yes No Unknown
-

**6. If answered "Died" to [1a] then:
Has this death been discussed as part of a local morbidity/mortality meeting which included the patient's multiprofessional team?**

- Yes No Unknown
-

**7a. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:
What was the date of discharge from this hospital?**

**7b. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:
What was the time of discharge from this hospital?**

**8. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:
What type of long term ventilation was delivered at discharge from this hospital?**

- Invasive ventilation Non-invasive ventilation Unknown
-

**9a. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:
What was the level of dependency on LTV?**

Please see definitions: <https://www.ncepod.org.uk/ltv.html>

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

**9b. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:
What was the number of hours of ventilator-free breathing per day?**

Hours Unknown

10a.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:

Were there any delays in organising discharge?

- Yes No Unknown

10b.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [10a] then:

What do you attribute these delays to? (Please tick all that apply)

- Clinician or carer risk assessments
- Need for additional training/team competences
- Communication between teams
- Additional structural changes to patient environment
- Additional equipment
- Change of residence
- Breakdown of prior/previous care arrangements whilst an inpatient

Please specify any additional options here...

10c.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [10a] then:

If YES, please give further detail:

10d.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:

Were there any additional problems in relation to discharge from this hospital?

- Yes No Unknown

10e.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [10d] then:

If YES, please give details:

11a. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:

Were there any problems in relation to patient safety?

- Yes No Unknown

11b. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [11a] then:

If YES, please give details:

12a. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:

Was a discharge summary or equivalent provided at discharge from this hospital?

- Yes No Unknown

12b. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:

Was a revised care plan provided at discharge from this hospital?

- Yes No Unknown
 NA - transferred out

12c. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [12a] then:

If YES, which members of the multi-professional team received a copy of the discharge plan?

- | | | |
|--|--|--|
| <input type="checkbox"/> General Practitioner | <input type="checkbox"/> Paediatrician | <input type="checkbox"/> Respiratory physician |
| <input type="checkbox"/> Paediatric intensivist | <input type="checkbox"/> Intensivist | <input type="checkbox"/> Specialist tracheostomy nurse |
| <input type="checkbox"/> Specialist other nurse | <input type="checkbox"/> Physiotherapist | <input type="checkbox"/> Occupational therapist |
| <input type="checkbox"/> Speech & language therapist | <input type="checkbox"/> Otorhinolaryngologist | <input type="checkbox"/> Community based team |
| <input type="checkbox"/> Patient and Parent Carers | <input type="checkbox"/> Dietitian | <input type="checkbox"/> NA - transferred out |
| <input type="checkbox"/> None | <input type="checkbox"/> Not documented | |

Please specify any additional options here...

13. If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] then:

Was the patient discharged from their usual LTV centre?

- Yes No Unknown
-

**14a.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] then:
Were there any significant changes made to long term respiratory care during this admission?**

- Yes No Unknown

**14b.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] and "Yes" to [14a] then:
If YES, did these relate to: (please tick all that apply)**

- | | |
|---|---|
| <input type="checkbox"/> Care leadership (including transition of care) | <input type="checkbox"/> Ventilatory care |
| <input type="checkbox"/> Escalation plan | <input type="checkbox"/> Suction/airway clearance |
| <input type="checkbox"/> Humidification | <input type="checkbox"/> Mask type/fit |
| <input type="checkbox"/> Tracheostomy tube | <input type="checkbox"/> Antibiotic use |
| <input type="checkbox"/> Oxygen prescription | |

Please specify any additional options here...

14c.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] and "Yes" to [14a] and "Ventilatory care" to [14b] then:

If there were significant changes/adjustments to ventilator care made during this admission what were they? (Please tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Change of ventilator type | <input type="checkbox"/> Change of ventilation mode(s) |
| <input type="checkbox"/> Change of daily duration of ventilation | <input type="checkbox"/> Additional oxygen |

Please specify any additional options here...

**15a.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] then:
Were there significant changes to overall (non LTV) care?**

- Yes No Unknown

**15b.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] and "Yes" to [15a] then:
If YES what were they? (Please specify)**

**16a.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] then:
Were any decisions made about long term goals of treatment during this admission?**

- Yes No Unknown

**16b.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] and "Yes" to [16a] then:
If YES, what were these? (Please specify)**

**16c.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] and "Yes" to [16a] then:
If YES, where significant changes were made in any areas of care/goals of treatment were these clearly documented in a discharge plan?**

- Yes No Unknown

**16d.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] and "Yes" to [16a] then:
If YES, was a revised care plan communicated and fully accessible to family/carers at discharge?**

- Yes No Unknown

**16e.If answered "Discharged alive - normal residence", "Discharge alive - another hospital (LTV centre)", "Discharged alive (non LTV centre)", "Discharged alive - hospice" or "Discharged alive - other" to [1a] and "Yes" to [13] and "Yes" to [16a] then:
If YES, was a revised care plan communicated and fully accessible to the multi-professional team and carers at discharge?**

- Yes No Unknown