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.
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 patient's 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)
- [ ] Respiratory muscle weakness
- [ ] Central drive
- [ ] Upper airway obstruction
- [ ] Skeletal deformity e.g. Scoliosis
- [ ] Spinal cord injury
- [ ] Obesity hypoventilation
- [ ] Neurodisability
- [ ] Unknown

Please specify any additional options here...

8. Did this patient have other significant co-morbidities/associated problems? (Please tick all that apply)
- [ ] Poor cough
- [ ] Poor cough
- [ ] Nutritional problems
- [ ] Unsafe swallow
- [ ] Congenital abnormalities of Head/Neck
- [ ] None
- [ ] 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...
E. ARRIVAL

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
   - Another hospital
   - Hospice/Respite care
   - LTV unit
   - 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

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?

- Critical care medicine
- Paediatrics
- Paediatric cardiology
- Accident and emergency (A&E)
- General medicine
- Respiratory medicine
- Rehabilitation
- Ear, nose and throat (ENT)
- Anaesthetics
- Other
- Paediatric intensive care
- Paediatric respiratory medicine
- Paediatric neurology
- Paediatric cardiology
- Acute internal medicine
- Neurology
- Palliative medicine
- Paediatric surgery
- General surgery

6. Where was the patient first assessed on arrival?

- Emergency Department
- Paediatric Critical Care unit - Level 1
- Paediatric Critical Care unit - Level 3
- Adult (General) Critical Care unit - Level 3
- Specialist respiratory ward
- Admissions unit
- Paediatric Critical Care unit - Level 2
- Adult (General) Critical Care unit - Level 2
- Neonatal unit
- 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
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
   - Emergency surgery
   - Planned respiratory review
   - Respite care
   - 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?

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?

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?
☐ 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...

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?
   O Yes  O No  O Unknown

6b. If answered "Yes" to [1] and "Yes" to [6a] then:
   If YES, what were these? (Please tick all that apply)
   O Availability of carers/breakdown of care team or leadership
   O Family issues
   O Lack of local respite care
   O Unknown

   Please specify any additional options here...

7a. If answered "Yes" to [1] then:
   Could this admission have been anticipated?
   O Yes  O No  O Unknown  O 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?
   O Yes  O No  O Unknown  O 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?
   O Yes  O No  O 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):
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?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Invasive ventilation</th>
<th>Non-invasive ventilation</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th>High (Level 1)</th>
<th>Severe (Level 2)</th>
<th>Priority (Level 3)</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Hours</th>
<th>Unknown</th>
</tr>
</thead>
</table>
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?
- General Practitioner
- Paediatric intensivist
- Specialist other nurse
- Speech & language therapist
- Patient and Parent Carers
- None
- Paediatrician
- Intensivist
- Physiotherapist
- Otorhinolaryngologist
- Dietitian
- Respiratory physician
- Specialist tracheostomy nurse
- Occupational therapist
- Community based team
- NA – transferred out
- Not documented
- Patient and Parent Carers

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", "Discharged 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)
☐ Care leadership (including transition of care)  ☐ Ventilatory care
☐ Escalation plan  ☐ Suction/airway clearance
☐ Humidification  ☐ Mask type/fit
☐ Tracheostomy tube  ☐ Antibiotic use
☐ 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)
☐ Change of ventilator type  ☐ Change of ventilation mode(s)
☐ Change of daily duration of ventilation  ☐ 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)

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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)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>