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?
This form is to be completed for the admission where a tracheostomy insertion took place and where the intention was to use it to provide invasive ventilation (irrespective of whether it was anticipated to be LTV at the outset). It should be completed by a clinician involved in the team caring for the patient at the time of the tracheostomy insertion for example in critical care or ENT surgery. The admission during which the tracheostomy insertion took place will be referred to throughout this questionnaire as the ‘index admission’.

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.
1a. Professional group

1b. Grade

1c. Specialty

2. 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. LEAD CLINICIAN/TEAM DETAILS

1a. Are you the lead LTV clinician/team providing the patient’s usual LTV care?
   - ☐ Yes
   - ☐ No

1b. If answered "No" to [1a] then:
   If NO, (you are not this patient’s lead LTV CLINICIAN/TEAM) please provide details of the Hospital/Site where the patient’s usual lead LTV clinician is based:
   (Please do not supply clinician names)

1c. If answered "No" to [1a] then:
   If NO, (you are not this patient’s lead LTV CLINICIAN/TEAM) please provide details of the Trust/Health Board where the patient’s usual lead LTV clinician is based:
   (Please do not supply clinician names)
### D. PATIENT SPECIFIC DETAILS

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

- [ ] Yes
- [ ] No
- [ ] Unknown

1b. If answered "Yes" to [1a] then:
   If YES, please specify the age in years

   [ ] Unknown

   Value should be no more than 25

1c. If answered "No" to [1a] then:
   If NO, please specify the age in months

   [ ] Unknown

   Value should be no more than 24

2a. Was the patient aged ≥2 years when the LTV programme began?

- [ ] Yes
- [ ] No
- [ ] Unknown

2b. If answered "Yes" to [2a] then:
   If YES, please specify the age in years

   [ ] Unknown

   Value should be no more than 25

2c. If answered "No" to [2a] then:
   If NO, please specify the age in months

   [ ] Unknown

   Value should be no more than 24

3. Gender

- [ ] Male
- [ ] Female
- [ ] Unknown

4. Weight at the time of LTV initiation?

   [ ] Unknown
   kg
E. PATIENT CONDITION PRIOR TO TRACHEOSTOMY INSERTION

1. What was the principal diagnosis which led to the index admission? (Please specify)

2. 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

   Please specify any additional options here...

3. Did the patient have any other significant co-morbidities? (Please tick all that apply)
   - Poor cough
   - Nutritional problems
   - Unsafe swallow
   - Congenital abnormalities of Head/Neck
   - None

   Please specify any additional options here...

4a. Was the patient dependent on other technologies?
   - Yes
   - No
   - Unknown

4b. If answered "Yes" to [4a] then:
   If YES, please specify: (please tick all that apply)
   - Artificial feeding – tube
   - Artificial feeding - PEG/RIG/PEJ
   - Wheelchair
   - Devices to assist with communication, hearing or vision
   - Cough assist

   Please specify any additional options here...
1. What was the date and time of the admission?

2a. Please indicate the type of hospital where the tracheostomy insertion was undertaken:

- DGH <500 beds
- DGH ≥500 beds
- Specialist Paediatric Tertiary Centre
- University Teaching Hospital
- Independent Hospital
- Unknown

If not listed above, please specify here...

2b. How far is this hospital from the patient’s home?

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

3a. What type of centre is this hospital?

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

- Non LTV* centre
- LTV* centre
- Unknown

3b. If this is not an LTV centre for this age group was tracheostomy discussed with the lead local/regional provider for LTV?

- Yes
- No
- Unknown

If this is not an LTV centre for this age group was tracheostomy discussed with the lead local/regional provider for LTV?

4. What was the date of the tracheostomy insertion?

5a. What was the date when the patient was first ventilated prior to the tracheostomy insertion? (Final episode of ventilation)

5b. Where was care provided immediately prior to the decision to undertake tracheostomy insertion?

- 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
- Neonatal unit
- Adult (General) Critical Care unit - Level 3
- Specialist respiratory ward

If not listed above, please specify here...

5c. Had there been attempts to wean the patient from ventilation during this admission, prior to the tracheostomy insertion being undertaken?

- Yes
- No
- Unknown

5d. If answered “Yes” to [5c] then:

If YES, how many failed weaning attempts on this admission were there?

Attempts

- Unknown

5e. If answered “Yes” to [5c] then:

If YES, did the weaning attempt involve a trial of extubation?

- Yes
- No
- Unknown
G. ANTICIPATED LEVEL OF DEPENDENCY ON LTV

1a. What was the anticipated level of dependency on LTV following tracheostomy insertion?

Please see definitions

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

1b. What was the anticipated number of hours of ventilator free breathing per day?

Unknown

2. When the tracheostomy was inserted with a view to commence LTV, was it:

- As a bridge to definitive therapy or in anticipation of recovery with growth
- As “Destination” therapy (with no immediate plan to discontinue)
- Unknown
H. TRACHEOSTOMY INSERTION DETAILS AND INITIAL AFTER CARE

It is understood that the decision to perform a tracheostomy insertion is a process and that the timing of specific decisions and events may be difficult to provide accurately in retrospect. Patients may be ventilated for some period before a formal decision to undertake tracheostomy insertion is made or there may be evidence of deteriorating respiratory function. We would ask that clinicians provide information with as much accuracy as possible and refer to clinical records from the time.

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 ventilatory support (not home oxygen).

1. Prior to this admission had the need for a tracheostomy been anticipated?
   - Yes
   - No
   - Unknown

2a. Did the patient require additional oxygen when the tracheostomy insertion was undertaken?
   - Yes
   - No
   - Unknown

2b. If answered "Yes" to [2a] then:
   If YES what was the inspired oxygen when the tracheostomy was inserted?
   
   kPa

3. What was the date of tracheostomy insertion?

4a. What was the grade of the clinician performing the tracheostomy insertion?
   - 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...
4b. What was the speciality of the clinician performing the tracheostomy insertion?

- Critical care medicine
- Paediatrics
- Paediatric cardiology
- Accident and emergency (A&E)
- General medicine
- Respiratory medicine
- Rehabilitation
- Ear, nose and throat (ENT)
- Anaesthetics
- Unknown

If not listed above, please specify here...

4c. Did the operator form a part of the multi-professional decision-making process prior to the procedure?

- Yes
- No
- Unable to answer

5. What was/were the indication(s) for tracheostomy insertion?

- LTV
- Absent/ineffective cough
- Difficult / unsafe airway
- Unknown

Please specify any additional options here...

6. What was the urgency of the procedure?

- Scheduled/Elective
- Urgent/Emergency
- Unknown

7. Was the patient considered potentially difficult for tracheostomy insertion? (i.e. a “difficult airway”)

- Yes
- No
- Unknown

8. What type of tracheostomy insertion was performed?

- Percutaneous
- Surgical
- Unknown

9a. Were there any delays organising and/or performing the tracheostomy insertion?

- Yes
- No
- Unknown

9b. If answered "Yes" to [9a] then:
- If YES, please give details:
10a. Were there any immediate complications?

☐ Yes  ☐ No  ☐ Unknown

10b. If answered "Yes" to [10a] then:
If YES, did these relate to (please tick all that apply):

☐ Bleeding – minor  ☐ Bleeding - Major (requiring return to theatre)
☐ Obstruction  ☐ Accidental decannulation
☐ Air leaks (pneumothorax, surgical emphysema)
☐ Infection - local  ☐ Infection – mediastinitis
☐ Infection - respiratory  ☐ Aspiration
☐ Tracheal damage  ☐ Unknown

Please specify any additional options here...

10c. If answered "Yes" to [10a] then:
Did any of these complications require an escalation of care? (Return to theatres, transfer or increased level of care)

☐ Yes  ☐ No  ☐ Unknown
I. CONSENT FOR TRACHEOSTOMY INSERTION

1. What date was the consent form signed?

2a. What risks were discussed /documented?

- Bleeding - minor
- Obstruction
- Air leaks (pneumothorax, surgical emphysema)
- Infection - local
- Infection - respiratory
- Tracheal damage
- Unknown

Bleeding - major (requiring return to theatre)
Accidental decannulation
Infection - mediastinitis
Aspiration
Death

Please specify any additional options here...

2b. Was LTV specifically listed on the consent form as an indication for tracheostomy?

- Yes
- No
- Unknown

3a. What was the grade of the clinician who signed the consent form?

- 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)
- Unknown

If not listed above, please specify here...

3b. What was the specialty of the clinician who signed the consent form?

- Critical care medicine
- Paediatrics
- Paediatric cardiology
- Accident and emergency (A&E)
- General medicine
- Respiratory medicine
- Rehabilitation
- Ear, nose and throat (ENT)
- Anaesthetics
- Unknown

- Paediatric intensive care
- Paediatric respiratory medicine
- Paediatric neurology
- Paediatric cardiology
- Acute internal medicine
- Neurology
- Palliative medicine
- Paediatric surgery
- General surgery

If not listed above, please specify here...

4a. Was the patient able to fully participate in the consent process?

- Yes
- No
- Unknown
4b. If answered "No" to [4a] then:
   If NO was this because: (Please tick all that apply)
   □ Patient was considered too young to participate in this discussion
   □ Patient lacked competence/capacity
   □ Patient had specific communication difficulties
   □ Unknown

   Please specify any additional options here...

4c. If answered "No" to [4a] and "Patient lacked competence/capacity" to [4b] then:
   If the patient did not have competence/capacity was this clearly documented as part of
   the consent process?
   □ Yes  □ No  □ Unknown

4d. If answered "Yes" to [4a] then:
   If YES (the patient participated in the discussion and consent process prior to
   tracheostomy insertion) was this documented in the notes and/or on the consent form?
   □ Yes  □ No  □ Unknown
This section should be completed if the primary intention was to complete tracheostomy for LTV at the outset

1a. Was the primary intention at the outset to complete a tracheostomy insertion to provide long-term ventilation?
   - Yes
   - No
   - Unknown

1b. If answered "Yes" to [1a] then:
   Is there a clear record of how and when the decision to undertake tracheostomy insertion for LTV was made?
   - Yes
   - No
   - Unknown

2. If answered "Yes" to [1a] then:
   What was the date that it was clear that a tracheostomy would be required?

3. If answered "Yes" to [1a] then:
   How was the decision made to undertake tracheostomy insertion?

4a. If answered "Yes" to [1a] then:
   Was a multi-professional meeting held to discuss tracheostomy insertion and long-term ventilation?
   - Yes
   - No
   - Unknown

4b. If answered "Yes" to [4a] and "Yes" to [1a] then:
   Who was present? (Please tick all that apply)
   - Paediatrician
   - Intensivist
   - Physiotherapist
   - Dietician or nutritional team
   - Psychologist
   - Patient
   - Respiratory physician
   - Specialist tracheostomy nurse
   - Occupational therapist
   - Otorhinolaryngologist
   - Patient advocate
   - Parent Carers
   - Paediatric intensivist
   - Specialist other nurse
   - Speech & language therapist
   - Community based team
   - Social worker
   - Not documented

5a. If answered "Yes" to [1a] then:
   Was the patients GP included in the MDT decision making process to undertake tracheostomy insertion and commence LTV?
   - Yes
   - No
   - Unknown

5b. If answered "No" to [5a] and "Yes" to [1a] then:
   If NO, was the patient’s GP informed of the decision to perform a tracheostomy insertion and commence LTV?
   - Yes
   - No
   - Unknown
5c. If answered "Yes" to [1a] then:
Was the patients GP informed of the tracheostomy insertion and the decision to commence LTV prior to the patient leaving this unit?
- Yes
- No
- Unknown

6a. If answered "Yes" to [1a] then:
Were the implications of ongoing tracheostomy care at home discussed with the parent/carers?
- Yes
- No
- Unknown

6b. If answered "Yes" to [6a] and "Yes" to [1a] then:
If YES what was discussed? (Please tick all that apply)
- Long term/life-long need for tracheostomy care
- Possible critical incidents
- Modifications to home environment
- Need for additional 24/7 care
- Escalation of care when problems arise
- Immediate tracheostomy problems
- Early tracheostomy problems
- Length of hospital stay post-insertion
- Long-term tracheostomy problems, e.g. gastric distension, secretion clearance
- Long-term outcome of underlying condition(s)
- Unknown

Please specify any additional options here...

6c. If answered "Yes" to [6a] and "Yes" to [1a] then:
When was tracheostomy insertion and LTV first discussed with the patient/parent/carers?

6d. If answered "Yes" to [6a] and "Yes" to [1a] then:
How many conversations did the team making the decision to undertake tracheostomy insertion and commence LTV have with patient/parent/carers prior to the decision being made?

7a. If answered "Yes" to [1a] then:
Were there any differences of opinion between clinicians about whether tracheostomy was the most appropriate treatment decision for this patient?
- Yes
- No
- Unknown

7b. If answered "Yes" to [7a] and "Yes" to [1a] then:
If YES how were these resolved? (Please tick all that apply)
- Involvement of a Clinical ethics committee
- External Mediation
- Formal multidisciplinary discussion
- Informal multidisciplinary discussion
- Within hospital second opinion
- NA - Tracheostomy was inserted without consideration of LTV need
- NA - Remain unresolved
- Unknown

Please specify any additional options here...
7c. If answered "Yes" to [7a] and "Yes" to [1a] then:
If YES, please give further details:

7d. If answered "Yes" to [7a] and "Yes" to [1a] then:
If YES, did this result in significant delays in tracheostomy insertion?
☐ Yes ☐ No ☐ Unknown

8a. If answered "Yes" to [1a] then:
Were there any differences of opinion between clinicians and parent carers or the patient about whether tracheostomy was the most appropriate treatment modality for this patient?
☐ Yes ☐ No ☐ Unknown

8b. If answered "Yes" to [8a] and "Yes" to [1a] then:
If YES how were these resolved? (Please tick all that apply)
☐ Involvement of a Clinical ethics committee ☐ External Mediation
☐ Formal multidisciplinary discussion ☐ Informal multidisciplinary discussion
☐ Within hospital second opinion ☐ Ongoing access to psychological support
☐ Unknown

Please specify any additional options here...

8c. If answered "Yes" to [8a] and "Yes" to [1a] then:
If YES, please give further details:

8d. If answered "Yes" to [8a] and "Yes" to [1a] then:
If YES, did this result in significant delays in tracheostomy insertion?
☐ Yes ☐ No ☐ Unknown

9a. If answered "Yes" to [1a] then:
Was the patient given written/other media information to view prior to the decision to undertake tracheostomy insertion and commence LTV being made?
☐ Yes ☐ No ☐ Unknown ☐ Not applicable
9b. If answered "Yes" to [1a] then:
Were parent carers given written/other media information to view prior to the decision being made to undertake tracheostomy insertion and commence LTV?

- [ ] Yes
- [ ] No
- [ ] Unknown
- [ ] Not applicable
K. ONGOING TRACHEOSTOMY CARE POST INSERTION

1. Please specify the date the patient was established on a stable level of long-term ventilation (i.e. fit to step down to Level 2 care or less):

2a. How was the adequacy of ventilation following tracheostomy insertion at the point of step down of care assessed? (Please tick all that apply)

- Capnography
- Blood gases
- Oximetry
- Tidal volume measurements
- Leak measurements
- Visual chest movement
- Patient wellbeing
- Unknown

Please specify any additional options here...

2b. How would the adequacy of ventilation be assessed as a routine hereafter?

- Capnography
- Blood gases
- Oximetry
- Tidal volume measurements
- Leak measurements
- Visual chest movement
- Patient wellbeing
- Unknown

Please specify any additional options here...

2c. How often (routinely) was this planned to be assessed after discharge to home/community care?

- Monthly
- 3 monthly
- 6 monthly
- Annually
- Unknown
L. ONGOING CARE AND DISCHARGE

Please answer these questions irrespective of whether the patient has been discharged as yet for LTV to the intended home/community location

1a. After tracheostomy insertion, was the patient discharged to another location in your hospital?
   - Yes
   - No
   - Unknown

1b. If answered "Yes" to [1a] then:
   If YES, was this to a specialist respiratory ward?
   - Yes
   - No
   - Unknown

1c. If answered "Yes" to [1a] then:
   If YES, were there any specific problems relating to the tracheostomy following discharge to another ward?
   - Yes
   - No
   - Unknown

1d. If answered "Yes" to [1a] and "Yes" to [1c] then:
   If YES, what were these? (Please tick all that apply)
   - Bleeding - minor
   - Bleeding - Major (requiring return to theatre)
   - Obstruction
   - Accidental decannulation
   - Air leaks (pneumothorax, surgical emphysema)
   - Infection - local
   - Infection - mediastinitis
   - Infection - respiratory
   - Aspiration
   - Tracheal damage
   - Problems with tube changes
   - Unknown
   Please specify any additional options here...

2a. If answered "Yes" to [1a] then:
   What size of tracheostomy was in place at discharge?
   mm
   - Unknown

2b. If answered "Yes" to [1a] then:
   Was this a cuffed or uncuffed tube?
   - Cuffed
   - Uncuffed
   - Unknown

3a. What was the outcome of the admission?
   - Discharged alive - normal residence
   - Discharged alive (non LTV centre)
   - Discharged alive - hospice
   - Still an inpatient
   - Died
   - Unknown
   Please specify any additional options here...

3b. If answered "Discharged alive - normal residence", "Discharged alive (non LTV centre)" or "Discharged alive - hospice" to [3a] then:
   If DISCHARGED ALIVE, what was the date of discharge?

3c. If answered "Died" to [3a] then:
   If DIED, what was the date of death?
4a. Did the patient have a care package at discharge which clearly specified their tracheostomy needs?
- Yes
- No
- Unknown
- Not applicable

4b. If answered "Yes" to [4a] then:
If YES, did this include a tracheostomy "passport" or similar?
- Yes
- No
- Unknown
- Not applicable

A tracheostomy passport as "a readily accessible short document/card which specifies size and type of tracheostomy tube and any special requirements."

5a. Were there/have there been any CLINICAL problems with delivery of invasive ventilation prior to discharge/whilst waiting for discharge?
- Yes
- No
- Unknown
- Not applicable

5b. If answered "Yes" to [5a] then:
If YES did these/have these resulted in any delays in discharge/planning discharge?
- Yes
- No
- Unknown
- Not applicable

5c. If answered "Yes" to [5a] then:
If YES, to what do you attribute these delays: (please tick all that apply)
- Clinician or carer risk assessments
- Team competencies/need for additional training
- Difficulties with communication between teams
- Additional equipment
- Additional structural changes to patient environment
- Re-housing
- Need to agree funding for increased care package
- Unknown
- Not applicable

Please specify any additional options here...

5d. If answered "Yes" to [5a] then:
If YES, in your opinion what could have been done to reduce these delays?

6a. Does/Did the patient have any NON-CLINICAL problems which contributed to a delay in discharge?
- Yes
- No
- Unknown
- Not applicable

6b. If answered "Yes" to [6a] then:
If YES, did these/have these resulted in any delays in discharge/planning discharge?
- Yes
- No
- Unknown
- Not applicable
6c. If answered "Yes" to [6a] then:  
If YES, to what do you attribute these delays:  
☐ Clinician or carer risk assessments  
☐ Team competencies/need for additional training  
☐ Difficulties with communication between teams  
☐ Additional equipment  
☐ Additional structural changes to patient environment  
☐ Re-housing  
☐ Need to agree funding for increased care package  
☐ Unknown  
☐ Not applicable  

Please specify any additional options here...

6d. If answered "Yes" to [6a] then:  
If YES, in your opinion what could have been done to reduce these delays?

7a. Was there any disagreement about the safety of discharge?  
☐ Yes  ☐ No  ☐ Unknown  ☐ Not applicable  

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

8a. Was an emergency health care plan provided at discharge?  
☐ Yes  ☐ No  ☐ Unknown  ☐ Not applicable  

8b. If answered "Yes" to [8a] then:  
If YES, were the patient's family and care team provided with a copy of this?  
☐ Yes  ☐ No  ☐ Unknown  ☐ Not applicable  

8c. If answered "Yes" to [8a] then:  
If YES, was the patient's GP provided with a copy of this plan?  
☐ Yes  ☐ No  ☐ Unknown  ☐ Not applicable
9. Did the patient have a tracheostomy passport at discharge?

☐ Yes  ☐ No  ☐ Unknown

Many thanks for taking the time to complete this questionnaire