Long-term ventilation: Insertion of tracheostomy 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?

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.

B. CLINICIAN DETAILS AND STRUCTURED COMMENTARY

La.	Professional group
b.	Grade
c.	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?	
	O Yes	○ No	
1b.		nis patient's lead LTV CLINICIAN/TEAM) please provide det the patient's usual lead LTV clinician is based:	ails of the
1c.		nis patient's lead LTV CLINICIAN/TEAM) please provide deta here the patient's usual lead LTV clinician is based:	ails of the

D. PATIENT SPECIFIC DETAILS

та.	Yes	nt aged ≥2 years at th () No	Unknown
1b.	If answered "Y	es" to [1a] then: specify the age in yea	
			Years Unknown
	Value should be no r	more than 25	
1c.		lo" to [1a] then: pecify the age in mon	ths
		ľ	Months Unknown
	Value should be no r	more than 24	
2a.	Was the patier	nt aged ≥2 years wher	n the LTV programme began?
	O Yes	O No	O Unknown
2b.		es" to [2a] then: specify the age in yea	rs
			Years Unknown
	Value should be no r		
2c.		lo" to [2a] then: pecify the age in mon	ths
		٦	Months Unknown
	Value should be no n	more than 24	
3.	Gender		
	O Male	Female	O Unknown
4.	Weight at the	time of LTV initiation?	
			kg Unknown

E. PATIENT CONDITION PRIOR TO TRACHEOSTOMY INSERTION

 What were the main underlying sy (Please tick all that apply) 	rstem failure (s) which led to this patient needing LTV
Respiratory muscle weakness	Central drive
Upper airway obstruction	Skeletal deformity e.g. Scoliosis
Spinal cord injury	Obesity hypoventilation
☐ Neurodisability	
Please specify any additional options h	nere
rease specify any additional options in	
Trease speerly any additional options in	
	nificant co-morbidities? (Please tick all that apply)
B. Did the patient have any other sig	nificant co-morbidities? (Please tick all that apply)
. Did the patient have any other sig Poor cough Nutritional problems	nificant co-morbidities? (Please tick all that apply)
. Did the patient have any other sig	nificant co-morbidities? (Please tick all that apply)
. Did the patient have any other sig Poor cough Nutritional problems	nificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck
. Did the patient have any other sig Poor cough Nutritional problems None	nificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck
B. Did the patient have any other sig Poor cough Nutritional problems None	nificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck
B. Did the patient have any other sig Poor cough Nutritional problems None	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck here
B. Did the patient have any other sig Poor cough Nutritional problems None Please specify any additional options h	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck here
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Poor cough Nutritional problems None Please specify any additional options he Was the patient dependent on oth Yes No	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck here Der technologies? Unknown
Poor cough Nutritional problems None Please specify any additional options he Nose Nose Please specify any additional options he Nose Nose Nose Nose Nose Artificial feeding - tube	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck here Der technologies? Unknown
Poor cough Nutritional problems None Please specify any additional options he Nose Nose Please specify any additional options he Nose Nose Nose Artificial feeding - tube Artificial feeding - PEG/RIG/PEJ	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck here Der technologies? Unknown
Poor cough Nutritional problems None Please specify any additional options he No Yes No If answered "Yes" to [4a] then: If YES, please specify: (please tick Artificial feeding - tube Artificial feeding - PEG/RIG/PEJ Wheelchair	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck mere Der technologies? Unknown all that apply)
Poor cough Nutritional problems None Please specify any additional options he Nose Nose Please specify any additional options he Nose Nose Nose Artificial feeding - tube Artificial feeding - PEG/RIG/PEJ	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck mere Der technologies? Unknown all that apply)
Poor cough Nutritional problems None Please specify any additional options he Nose No Yes No If answered "Yes" to [4a] then: If YES, please specify: (please tick Artificial feeding - tube Artificial feeding - PEG/RIG/PEJ Wheelchair Devices to assist with communicat	Inificant co-morbidities? (Please tick all that apply) Unsafe swallow Congenital abnormalities of Head/Neck here Per technologies? Unknown a all that apply) ion, hearing or vision

F. ADMISSION

Please indicate the	type of hospital whe	re the tracheostomy insertion was underta	ken:
O DGH <500 beds O Specialist Paediat O Independent Hosp		DGH ≥500 bedsUniversity Teaching HospitalUnknown	
If not listed above, pl	ease specify here		
How far is this hos	pital from the patient	's home?	
<25 miles Unknown	O 25-50 miles	○ 50-100 miles ○ >100 miles	
. What type of centr * LTV centre is define their ventilatory care	ed as one which provides	this patient with the normal support and review	of of
O Non LTV* centre	O LTV* centre	O Unknown	
. If this is not an LTV local/regional provi		roup was tracheostomy discussed with the	lea
O Yes O Unknown		NoNA - is an LTV centre for this age group)
. What was the date	of the tracheostomy	insertion?	
. What was the date		insertion? s first ventilated prior to the tracheostomy	
. What was the date	when the patient was		
. What was the date insertion? (Final ep	when the patient was bisode of ventilation)		
. What was the date insertion? (Final epotential of the control of	when the patient was pisode of ventilation) ovided immediately particular of the control of the	rior to the decision to undertake tracheost O Paediatric Critical Care unit - Level 2 O Adult (General) Critical Care unit - Leve	omy
. What was the date insertion? (Final epoints of the control of th	when the patient was pisode of ventilation) ovided immediately partical Care unit - Level 1 Care unit - Level 3 ritical Care unit - Level 3 tory ward	rior to the decision to undertake tracheost O Paediatric Critical Care unit - Level 2 O Adult (General) Critical Care unit - Leve	omy
. What was the date insertion? (Final epoints of the control of th	when the patient was bisode of ventilation) ovided immediately particulated immediated immediately particulated immediated imme	rior to the decision to undertake tracheost O Paediatric Critical Care unit - Level 2 O Adult (General) Critical Care unit - Level O Neonatal unit	omy
. What was the date insertion? (Final epoints of the control of th	when the patient was pisode of ventilation) ovided immediately processed immediately pr	rior to the decision to undertake tracheost O Paediatric Critical Care unit - Level 2 O Adult (General) Critical Care unit - Level O Neonatal unit	omy
. What was the date insertion? (Final epure was care proinsertion? O Paediatric Critical O Paediatric Critical O Adult (General) C O Specialist respirate If not listed above, place I had there been attended of the trached of the t	when the patient was pisode of ventilation) ovided immediately pitched immediately pi	rior to the decision to undertake tracheost O Paediatric Critical Care unit - Level 2 O Adult (General) Critical Care unit - Level O Neonatal unit	omy
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. What was the date insertion? (Final epinosertion? . Where was care proinsertion? . Paediatric Critical . Paediatric Critical . Adult (General) C . Specialist respirate If not listed above, place If not listed above, place If answered "Yes" to the trached If Yes, how many face If answered "Yes" to the tracked If Yes, how many face If answered "Yes" to the tracked If Yes, how many face If answered "Yes" to the tracked If Yes, how many face If answered "Yes" to the tracked If Yes, how many face If answered "Yes" to the tracked If Yes, how many face If answered "Yes" to the tracked If Yes, how many face If answered "Yes" to the tracked If Yes, how many face If answered "Yes" to the tracked If If answered "Yes" to the tracked If	when the patient was pisode of ventilation) ovided immediately processed in the patient of the	rior to the decision to undertake tracheost Paediatric Critical Care unit - Level 2 Adult (General) Critical Care unit - Level Neonatal unit rient from ventilation during this admission gundertaken? Unknown ts on this admission were there?	omy

G. ANTICIPATED LEVEL OF DEPENDENCY ON LTV

1a.	What was the anticipated level of dependency on LTV following tracheostomy insertion? Please see definitions				
	O High (Level 1)	O Severe (Level 2)	O Priority (Level 3)	Unknown	
1b.	What was the antici	pated number of hours	of ventilator free brea	thing per day?	
		Hours	Unknown		
2.	When the tracheost	omy was inserted with	a view to commence L	ΓV, was it:	
	O As a bridge to defi	nitive therapy or in anticip	oation of recovery with gro	owth	
		nerapy (with no immediate	e 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).

O Yes	O		
	O No	O Unknown	
a. Did the patient re undertaken?	equire additional ox	ygen when the tracheostomy insertior	ı was
O Yes	O No	Unknown	
b. If answered "Yes If YES what was t		when the tracheostomy was inserted?	,
		kPa	
3. What was the dat	te of tracheostomy	nsertion?	
a. What was the gra	ade of the clinician _l	performing the tracheostomy insertion	?
a. What was the gra	ade of the clinician p	performing the tracheostomy insertion	?
ConsultantStaff grade/Asse	ociate specialist	performing the tracheostomy insertion	?
ConsultantStaff grade/AssoTrainee with CC	ociate specialist		?
ConsultantStaff grade/AssoTrainee with CCSenior specialis	ociate specialist CT st trainee (ST3+ or equ	ivalent)	?
ConsultantStaff grade/AsseTrainee with COSenior specialisJunior specialist	ociate specialist CT st trainee (ST3+ or equ t trainee (ST1&ST2 or e	nivalent) CT equivalent)	?
ConsultantStaff grade/AssoTrainee with COSenior specialistJunior specialistBasic grade (HO	ociate specialist CT It trainee (ST3+ or equ It trainee (ST1&ST2 or e D/FY1 or SHO/FY2 or ed	iivalent) CT equivalent) quivalent)	?
 Consultant Staff grade/Asso Trainee with CO Senior specialist Junior specialist Basic grade (HO Specialist Nurse 	ociate specialist CT It trainee (ST3+ or equ It trainee (ST1&ST2 or e D/FY1 or SHO/FY2 or eq It (Nurse consultant, no	iivalent) CT equivalent) quivalent) urse practitioner, clinical nurse specialist)	?
O Consultant O Staff grade/Asso O Trainee with CO O Senior specialist O Junior specialist O Basic grade (HO O Specialist Nurse O Senior staff nur	ociate specialist T It trainee (ST3+ or equality or equality or ST1&ST2 or equality or ST2 or equality or equali	iivalent) CT equivalent) quivalent) urse practitioner, clinical nurse specialist)	?
 Consultant Staff grade/Asse Trainee with CO Senior specialist Junior specialist Basic grade (HO Specialist Nurse Senior staff nur 1st Level nurse 	ociate specialist T It trainee (ST3+ or equations or equations) O/FY1 or SHO/FY2 or equations of equations or equations	iivalent) CT equivalent) quivalent) urse practitioner, clinical nurse specialist)	?
O Consultant O Staff grade/Asso O Trainee with CO O Senior specialist O Junior specialist O Basic grade (HO O Specialist Nurse O Senior staff nur	ociate specialist T It trainee (ST3+ or equations or equations) O/FY1 or SHO/FY2 or equations of equations or equations	iivalent) CT equivalent) quivalent) urse practitioner, clinical nurse specialist)	?

4b.	b. 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 		 Paediatric intensive care Paediatric respiratory medicine Paediatric neurology Paediatric cardiology Acute internal medicine Neurology Palliative medicine Paediatric surgery General surgery 		
	If not listed above, pleas	se specify here			
4c.	Did the operator form the procedure?	a part of the multi-pro	ofessional decision-making process prior to		
	O Yes	O No	O Unable to answer		
5.	What was/were the in LTV Unknown Please specify any addit	_	stomy insertion? ective cough Difficult / unsafe airway		
		O Urgent/Emergency	○ Unknowncult for tracheostomy insertion? (i.e. a○ Unknown		
8.	What type of tracheo Percutaneous	stomy insertion was pe O Surgical	erformed? () Unknown		
		Gurgical			
9a.	Were there any delay	s organising and/or pe	rforming the tracheostomy insertion?		
	O Yes	O No	O Unknown		
9b.	If answered "Yes" to If YES, please give de				

10a.Were there an	y immediate complica	tions?
O Yes	O No	O Unknown
10b.If answered "Y If YES, did the	'es" to [10a] then: se relate to (please ti	ck all that apply):
☐ Bleeding – n ☐ Obstruction ☐ Air leaks (pr	ninor neumothorax, surgical er	☐ Bleeding - Major (requiring return to theatre) ☐ Accidental decannulation nphysema)
☐ Infection - Id☐ Infection - re☐ Tracheal da	espiratory	Infection - mediastinitisAspirationUnknown
Please specify a	ny additional options he	re
_		ire an escalation of care? (Return to theatres,
O Yes	○ No	Unknown

I. CONSENT FOR TRACHEOSTOMY INSERTION

1. What date was the consent for	rm signea:
a. What risks were discussed /do	ocumented?
☐ Bleeding - minor ☐ Obstruction ☐ Air leaks (pneumothorax, surg ☐ Infection - local ☐ Infection - respiratory ☐ Tracheal damage ☐ Unknown Please specify any additional option	☐ Infection – mediastinitis ☐ Aspiration ☐ Death
b. Was LTV specifically listed on	the consent form as an indication for tracheostomy?
O Yes O No	O Unknown
 Consultant Staff grade/Associate specialis Trainee with CCT Senior specialist trainee (ST3+ Junior specialist trainee (ST1& Basic grade (HO/FY1 or SHO/F) Specialist Nurse (Nurse consul Senior staff nurse, enrolled nu 1st Level nurse, staff nurse (Red) Unknown 	F or equivalent) ST2 or CT equivalent) Y2 or equivalent) Itant, nurse practitioner, clinical nurse specialist) Irse (EN) etc)
If not listed above, please specify	here
Bb. What was the specialty of the 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	 Acute internal medicine Neurology Palliative medicine Paediatric surgery General surgery
	participate in the consent process?
O Yes O No	O Unknown

4b.	If answered "No" to [If NO was this because	4a] then: se: (Please tick all that	apply)
	Patient lacked comp	red too young to participa vetence/capacity communication difficultie	
	Please specify any addit	cional options here	
4c.		have competence/capa	l competence/capacity" to [4b] then: acity was this clearly documented as part of
	O Yes	O No	O Unknown
4d.		rticipated in the discus	ssion and consent process prior to ed in the notes and/or on the consent form?
	O Yes	O No	○ Unknown

J. DECISION TO UNDERTAKE TRACHEOSTOMY INSERTION AND LTV

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	1?		
	O Yes	O No	Unknown	
1b.	. If answered "Yes" to Is there a clear recor for LTV was made?		en: v and when the decision to und	ertake tracheostomy insertion
	O Yes	O No	O Unknown	
2.	. If answered "Yes" to What was the date ti		en: ens clear that a tracheostomy wo	ould be required?
3.	. If answered "Yes" to How was the decision		en: to undertake tracheostomy ins	ertion?
4a.			en: eting held to discuss tracheost	omy insertion and long-term
	ventilation? () Yes	∩ No	() Unknown	
4b.	. If answered "Yes" to	[4a] and	d "Yes" to [1a] then:	
	Who was present? (P	lease tid	ck all that apply)	
	☐ Paediatrician ☐ Intensivist ☐ Physiotherapist ☐ Dietician or nutritio ☐ Psychologist ☐ Patient	nal team		☐ Paediatric intensivist ☐ Specialist other nurse ☐ Speech & language therapist ☐ Community based team ☐ Social worker ☐ Not documented
5a.	. If answered "Yes" to Was the patients GP tracheostomy inserti	included	d in the MDT decision making p	rocess to undertake
	O Yes	O No	O Unknown	
		_		
5b.	. If answered "No" to [If NO, was the patien and commence LTV?		"Yes" to [1a] then: nformed of the decision to perf	orm a tracheostomy insertion

5C.	c. 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?				
	O Yes	O No	O Unknown		
6a.	. If answered "Ye Were the implic parent/carers?		cheostomy care at home discussed with the		
	O Yes	O No	O Unknown		
6b		s" to [6a] and "Yes" t discussed? (Please t			
	Possible critical Modifications Need for addit Escalation of o Immediate tra Early tracheos Length of hos Long-term tra Unknown	to home environment cional 24/7 care care when problems arise the case of the	se .g. gastric distension, secretion clearance ndition(s)		
	. If answered "Ye When was trach	<u> </u>	to [1a] then: and LTV first discussed with the patient/parent/carers?		
	. If answered "Ye When was trach . If answered "Ye How many conv	s" to [6a] and "Yes" to eostomy insertion ar s" to [6a] and "Yes" to ersations did the tea	to [1a] then: and LTV first discussed with the patient/parent/carers?		
	. If answered "Ye When was trach . If answered "Ye How many conv insertion and co	s" to [6a] and "Yes" to eostomy insertion ar s" to [6a] and "Yes" to ersations did the tea	to [1a] then: and LTV first discussed with the patient/parent/carers? to [1a] then: m making the decision to undertake tracheostomy		
6d.	If answered "Ye When was trach If answered "Ye How many convinsertion and comade? If answered "Ye Were there any	s" to [6a] and "Yes" to eostomy insertion are strongly insertion are strongly insertion are strongly insertions did the teat of the teat of the strongly insertions did the teat of the strongly insertions differences of opinions.	to [1a] then: and LTV first discussed with the patient/parent/carers? to [1a] then: m making the decision to undertake tracheostomy ith patient/parent/carers prior to the decision being		
6d. 7a.	If answered "Ye When was trach If answered "Ye How many convinsertion and comade? If answered "Ye Were there any was the most approximate of the company of the company was the most approximate of the company was the most approximate of the company of the comp	s" to [6a] and "Yes" to eostomy insertion are stone of the teather the teather the teather of the teather of the teather of the teather the teather the the teather of the	co [1a] then: nd LTV first discussed with the patient/parent/carers? co [1a] then: m making the decision to undertake tracheostomy ith patient/parent/carers prior to the decision being Unknown un between clinicians about whether tracheostomy decision for this patient? Unknown		

. If ans If YES O Ye . If ans Were about patie O Ye . If ans If YES Inv O Ur Please If YES . If ans If YES	swered "Yes" S, did this res swered "Yes" t there any d t whether tra ent? es swered "Yes" S how were t	No to [1a] then: ifferences of opinion bety	in tracheostomy insertion? O Unknown ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown then:
If YES O Ye If ans Were about patien O Ye If ans If YES O Ur Please If YES	swered "Yes" t whether tra es swered "Yes" t whether tra ent? es swered "Yes" S how were t	sult in significant delays No to [1a] then: ifferences of opinion betweeneostomy was the most	in tracheostomy insertion? O Unknown ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown then:
If YES Yes If ans Were about patien Yes If ans If YES Ur Please If ans If YES	swered "Yes" t whether tra es swered "Yes" t whether tra ent? es swered "Yes" S how were t	sult in significant delays No to [1a] then: ifferences of opinion betwacheostomy was the most	in tracheostomy insertion? O Unknown ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown then:
If YES Yes If ans Were about patien Yes If ans If YES Ur Please If ans If YES	swered "Yes" t whether tra es swered "Yes" t whether tra ent? es swered "Yes" S how were t	sult in significant delays No to [1a] then: ifferences of opinion betwacheostomy was the most	in tracheostomy insertion? O Unknown ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown then:
If YES Yes If ans Were about patien Yes If ans If YES Ur Please If YES	swered "Yes" t whether tra es swered "Yes" t whether tra ent? es swered "Yes" S how were t	sult in significant delays No to [1a] then: ifferences of opinion betwacheostomy was the most	in tracheostomy insertion? O Unknown ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown then:
If YES Yes If ans Were about patien Yes If ans If YES Ur Please If ans If YES	swered "Yes" t whether tra es swered "Yes" t whether tra ent? es swered "Yes" S how were t	sult in significant delays No to [1a] then: ifferences of opinion betwacheostomy was the most	in tracheostomy insertion? O Unknown ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown then:
If YES Yes If ans Were about patien Yes If ans If YES Ur Please If YES	swered "Yes" t whether tra es swered "Yes" t whether tra ent? es swered "Yes" S how were t	sult in significant delays No to [1a] then: ifferences of opinion betwacheostomy was the most	in tracheostomy insertion? O Unknown ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown then:
If ans Were about patie Ye If ans If YES Ur Please If ans If YES	swered "Yes" e there any d t whether tra ent? es swered "Yes" S how were t	to [1a] then: ifferences of opinion betweenches to the most opinion betweenches the most opinion betweenches to [1a]	ween clinicians and parent carers or the patie t appropriate treatment modality for this O Unknown
Were about paties Yes If ans If YES Ur Please If ans If YES	e there any det whether transfer ent? ess swered "Yes" S how were t	ifferences of opinion betweences of was the most open of the No No to [1a]	Unknown
Were about paties O Ye If ans If YES O Ur Please If ans If YES	e there any det whether transfer ent? ess swered "Yes" S how were t	ifferences of opinion betweences of was the most open of the No No to [1a]	Unknown
If ans If YES	swered "Yes" S how were t	to [8a] and "Yes" to [1a]	then:
If YES	S how were t		
Fo Will Ur Please			
Please If ans If YES	volvement of	a Clinical ethics committee	☐ External Mediation
Please If ans If YES		ciplinary discussion	☐ Informal multidisciplinary discussion
If ans If YES	nknown	second opinion	Ongoing access to psychological support
If YES	e specify any a	additional options here	
If YES			
. If ans		to [8a] and "Yes" to [1a] e further details:	then:
O Ye		to [8a] and "Yes" to [1a] sult in significant delays	
Was t	S, did this re		then: in tracheostomy insertion? O Unknown
O Ye	S, did this re	No to [1a] then: piven written/other media	in tracheostomy insertion?

		my insertion and commer	
Yes	O No	Unknown	Not applicable

K. ONGOING TRACHEOSTOMY CARE POST INSERTION

1.	Please specify the date the p ventilation (i.e. fit to step do			able level of long-ter	'm
2a.	How was the adequacy of ver step down of care assessed?			ny insertion at the po	oint of
	☐ Capnography	☐ Blood gases		☐ Oximetry	
	☐ Tidal volume measurements ☐ Patient wellbeing	Leak measu Unknown	rements	☐ Visual chest mover	ment
	Please specify any additional opt	ions here			
2b.	How would the adequacy of v	entilation be a	ssessed as a ro	utine hereafter?	
	☐ Capnography☐ Tidal volume measurements☐ Patient wellbeing	☐ Blood gases☐ Leak measu☐ Unknown		Oximetry Visual chest mover	nent
	Please specify any additional opt	ions here			
2c.	How often (routinely) was thi home/community care?	s planned to b	e assessed afte	r discharge to	
	O Monthly O 3 m	onthly	O 6 monthly	Annually	

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 ${\bf P}$

	hospital?		
	O Yes	O No	Unknown
١.	If answered "Yes" to If YES, was this to a s		piratory ward?
	O Yes	O No	Unknown
:.	If answered "Yes" to If YES, were there an to another ward?		oblems relating to the tracheostomy following discharge
	O Yes	O No	Unknown
١.	If answered "Yes" to If YES, what were the		
	☐ Bleeding - minor ☐ Obstruction ☐ Air leaks (pneumoth ☐ Infection - local ☐ Infection - respirator ☐ Tracheal damage ☐ Unknown	_	☐ Bleeding - Major (requiring return to theatre) ☐ Accidental decannulation emphysema) ☐ Infection - mediastinitis ☐ Aspiration ☐ Problems with tube changes
· ·	If answered "Yes" to What size of tracheos		
١.			place at discharge? mm Unknown
		stomy was in	mm Unknown
	What size of tracheos If answered "Yes" to	stomy was in	mm Unknown
o.	What size of tracheos If answered "Yes" to Was this a cuffed or to Cuffed	[1a] then: uncuffed tub	mm Unknown e? Unknown
).	What size of tracheos If answered "Yes" to Was this a cuffed or to	[1a] then: uncuffed tub Uncuffed ne of the adn	mm Unknown e? Unknown hission?
).	What size of tracheos If answered "Yes" to Was this a cuffed or o Cuffed What was the outcom Discharged alive - n Discharged alive - h	[1a] then: uncuffed tub Uncuffed ne of the adn ormal residen	mm Unknown e? Unknown Discharged alive (non LTV centre) Still an inpatient Unknown
o.	What size of tracheos If answered "Yes" to Was this a cuffed or to Cuffed Cuffed What was the outcom Discharged alive - h Died	[1a] then: uncuffed tub Uncuffed ne of the adn ormal residen	mm Unknown e? Unknown Discharged alive (non LTV centre) Still an inpatient Unknown
b.	If answered "Yes" to Was this a cuffed or u Cuffed What was the outcom Discharged alive - h Died Please specify any addit If answered "Discharged alive - he "Discharged alive - he	[1a] then: uncuffed tub Uncuffed ne of the adn ormal residen ospice tional options	Discharged alive (non LTV centre) Unknown Discharged alive (non LTV centre) Unknown Discharged alive (non LTV centre) Unknown Discharged alive (non LTV centre) Ormal residence", "Discharged alive (non LTV centre)" or
b.	If answered "Yes" to Was this a cuffed or u Cuffed What was the outcom Discharged alive - h Died Please specify any addit If answered "Discharged alive - he "Discharged alive - he	[1a] then: uncuffed tub Uncuffed ne of the adn ormal residen ospice tional options	mm Unknown e? Unknown hission? ce Discharged alive (non LTV centre) Still an inpatient Unknown here prmal residence", "Discharged alive (non LTV centre)" or al then:
b.	If answered "Yes" to Was this a cuffed or u Cuffed What was the outcom Discharged alive - h Died Please specify any addit If answered "Discharged alive - he "Discharged alive - he	[1a] then: uncuffed tub Uncuffed the adn ormal residen ospice tional options ged alive - no	Unknown Discharged alive (non LTV centre) Still an inpatient Unknown here Drmal residence", "Discharged alive (non LTV centre)" or a] then: he date of discharge?

4a. Did the patient have a care package at discharge which clearly specified their tracheostomy needs?					
	O Yes	O No	O Unknown	O Not applicable	
4b.	A tracheostomy passpor	[4a] then: e a tracheostomy "pass rt as "a readily accessible nd any special requiremen \(\) No	short document/card whi	ich specifies size and type O Not applicable	
5a.		e been any CLINICAL pr ilst waiting for dischar		of invasive ventilation	
	O Yes	O No	O Unknown	O Not applicable	
5b.	If answered "Yes" to If YES did these/have	[5a] then: these resulted in any c	lelays in discharge/pla	nning discharge?	
	O Yes	O No	O Unknown	O Not applicable	
5c.	If answered "Yes" to If YES, to what do you	[5a] then: u attribute these delays	s: (please tick all that a	apply)	
	Difficulties with com Additional equipmer Additional structural Re-housing	/need for additional trainin munication between team	onment		
	Please specify any addit	cional options here			
5d.	If answered "Yes" to If YES, in your opinion	[5a] then: n what could have been	done to reduce these	delays?	
6a.	Does/Did the patient discharge?	have any NON-CLINICA	L problems which cont	ributed to a delay in	
	O Yes	O No	O Unknown	O Not applicable	
6b.	If answered "Yes" to If YES, did these/have	[6a] then: e these resulted in any	delays in discharge/pla	anning discharge?	
	O Yes	O No	O Unknown	O Not applicable	

6c.	If answered "Yes" If YES, to what do	' to [6a] then: o you attribute thes	e delays:		
	Clinician or care	er risk assessments			
	_	ncies/need for additior			
	Additional equip	communication between	een teams		
		tural changes to patie	nt environment		
	Re-housing	and changes to pane			
	☐ Need to agree f	unding for increased o	care package		
	Unknown				
	■ Not applicable				
	Please specify any a	additional options her	e		
6d.	If answered "Yes" If YES, in your op		ve been done to reduce th	nese delays?	
7a.	_	_	he safety of discharge?	○ Not applicable	
	Was there any dis	O No	he safety of discharge? Unknown	Not applicable	
	O Yes	○ No ' to [7a] then:		O Not applicable	
	O Yes If answered "Yes"	○ No ' to [7a] then:		O Not applicable	
	O Yes If answered "Yes"	○ No ' to [7a] then:		○ Not applicable	
	O Yes If answered "Yes"	○ No ' to [7a] then:		○ Not applicable	
	O Yes If answered "Yes"	○ No ' to [7a] then:		O Not applicable	
7b.	Yes If answered "Yes" If YES, please spe	No ' to [7a] then: ecify:	Unknown	O Not applicable	
7b.	Yes If answered "Yes" If YES, please spe	No To [7a] then: ecify: To [7a] then: ecify:	Unknown provided at discharge?		
7b. 8a.	Yes If answered "Yes" If YES, please specific yes Was an emergence yes Yes If answered "Yes"	No ' to [7a] then: ecify: cy health care plan No ' to [8a] then:	Unknown provided at discharge? Unknown	○ Not applicable	
7b. 8a.	Yes If answered "Yes" If YES, please specific yes Was an emergence yes Yes If answered "Yes"	No ' to [7a] then: ecify: cy health care plan No ' to [8a] then:	Unknown provided at discharge?	○ Not applicable	
7b. 8a. 8b.	Was an emergence Yes If answered "Yes" Was an emergence Yes If answered "Yes" If YES, were the poor yes If answered "Yes"	No To [7a] then: Excify: To whealth care plan No To [8a] then: Datient's family and No To [8a] then:	provided at discharge? Unknown Care team provided with a	O Not applicable a copy of this?	
7b. 8a. 8b.	Was an emergence Yes If answered "Yes" Was an emergence Yes If answered "Yes" If YES, were the poor yes If answered "Yes"	No To [7a] then: Excify: To whealth care plan No To [8a] then: Datient's family and No To [8a] then:	provided at discharge? Unknown care team provided with a	O Not applicable a copy of this?	

O Yes	O No	O Unknown	
any thanks for t	aking the time to com	plete this questionnaire	