

Long-Term Ventilation

Protocol

Study Advisory Group Members

Ajit Thomas Consultant Respiratory Physician

Alice Joy Lay Representative

Andrew Bentley Consultant in Respiratory and Intensive Care Medicine (NTSP)

Andrew Selby Consultant in Paediatric Intensive Care

Anita Simonds Consultant in Respiratory and Sleep Medicine (BTS)

Anjay Pillai Consultant in Respiratory Paediatrics
Anne Gordon Consultant Occupational Therapist

Audrey Martin Physiotherapist (ACPRC)
Barbara Maxwell Paediatric Respiratory Nurse

Catherine Doherty Consultant Paediatric Anaesthetist (NTSP/APAGBI)

Catriona Johnson Associate Director (National Network Management Service)

Chris Carey Consultant Anaesthetist (SG)

Clare Halfhide Consultant in Paediatric Respiratory Medicine (BPRS)

Colin Wallis Consultant in Respiratory Paediatrics (RCPCH)

Constantinos Regas Lay Representative

Deborah Lynn Matron (Children's Hospice)
Elspeth Jardine Ventilation Service Coordinator

Fiona Finlay Consultant Community Paediatrician (BACCH)
Gillian Halley Consultant in Paediatric Intensive Care
Hasnaa Koch Consultant ENT Surgeon (ENT UK)

Ian Doughty Consultant Paediatrician (SG)

Jane Noyes Professor of Health and Social Services Research and Child Health

Jill Evans Patient Representative

Joanna Grant Director/RGN/RSCN Member of RCNCYP Continuing and

Community Care Forum (RCN)

Julian Forton Consultant in Paediatric Respiratory Medicine and Cystic Fibrosis (BPRS)

Linda Partridge Director of Programmes (WellChild)

National Children's Bureau

Nigel Buck Lay Representative
Patricia Hagan Clinical Commissioner

Phil Davies Operational Lead for long-term ventilation (SPS)

Rajesh Phatak Consultant Paediatric Intensivist (PICS)

Rhona Webster Clinical Commissioner
Ron Newall Lay Representative

Ruth Harte WellChild Community Paediatric Respiratory Nurse

Simon Baudouin Consultant in Critical Care Medicine (FICM)
Stacey Zimmels Speech and Language Therapist (RCSLT)

Trudy Ward Head of Children's Specialist and Community Nursing
Vicky Elliott Clinical Psychologist in Paediatrics (Long-Term Ventilation)

Clinical Coordinators

Mark Juniper Clinical Co-ordinator (Consultant in Intensive Care and Respiratory Medicine)

Kathy Wilkinson Clinical Co-ordinator (Consultant Paediatric Anaesthetist)

Rachael Moses Clinical Co-ordinator (Consultant Physiotherapist)

Non clinical staff

Heather Freeth Clinical Researcher
Nicholas Mahoney Research Assistant
Marisa Mason Chief Executive

Introduction

The number of children on long-term ventilation (LTV) in the UK has grown significantly in recent decades: in 1975 only one child was documented as being on LTV in the UK, by 2013 this number had increased to nearly 1400.¹ Long-term ventilation is considered to be ventilation provided every day for a minimum of 3 months.² Children on long-term ventilation include "any child who, when medically stable, continues to require a mechanical aid for breathing, after an acknowledged failure to wean, or a slow wean, three months after the institution of ventilation". ³

In practice the term "LTV" includes various types of long term respiratory support. Children and young people can be either invasively ventilated (via a tracheostomy) or non-invasively ventilated or have Continuous Positive Airway Pressure or "CPAP "(both generally using a breathing mask). Although these procedures/therapies are usually started in hospital, equipment can be provided for home CPAP or ventilation to be continued for all or part of the day. Indeed over the last two decades, long term respiratory support is now more commonly delivered at home.⁴ This means that the care pathway can include critical care services (paediatric and adult), acute paediatric and medical services and community care, including general practitioners and hospice/respite care and care provided by parent carers as well as those in transport services such as ambulances. With an increasing number of children and young people transitioning into adult life requiring LTV⁵ it is imperative that the current care pathways and support structures in place for this group are described and agreed by the patient / family.

Advances in technology have made the initiation of LTV a relatively straight forward procedure, however day to day problems still arise, for example mask fitting difficulties in very young children. The aim of LTV is to improve survival and quality of life. However there is a general belief that our understanding of the emotional and socio-economic journey for the patient and family has not kept pace.⁶ Loss of employment resulting in a reduction of family incomes, housing and social isolation along with difficulties accessing education and short break/respite care, have all been identified as issues facing those who care for children and young people-on LTV.⁷ However, there is little data on the adverse effect these issues have on family dynamics and the mental health of the patient, parents and siblings. The long term wellbeing of this group and their families need to be considered as well as the impact of outcomes such as readmission or death.

¹ NHS England, Children who are Long Term Ventilated – Pathfinder Project Engaging with Families and Children/Young People: An independent quality improvement review by the Patient Experience Network

² Palange, P. and Simonds, A.K. 2013. ERS Handbook of respiratory medicine, 2nd ed: p178

³ Jardine E, Wallis C. Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom. Thorax 1998;53:762-767

⁴ Jardine E, Wallis C. Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom. Thorax 1998;53:766-766

⁵ Robinson, R. Ventilator Dependency in the United Kingdom, *Archives of Disease in Childhood* 1990; 65: 1235-1236

⁶ NHS England, Children who are Long Term Ventilated – Pathfinder Project Engaging with Families and Children/Young People: An independent quality improvement review by the Patient Experience Network

⁷ Margolan H., Fraser J. and Lenton S., Parental experience of services when their child requires long-term ventilation. Implications for commissioning and providing services

Despite the numerous challenges that accompany LTV in the community, it is widely accepted that patients and their families benefit enormously from care at home rather than prolonged stays in hospital.⁸ Studies have shown that children who spend extended periods of time in a hospital setting can run into developmental and psychological challenges, and many caregivers have expressed a preference for home care.⁹ At-home-care ultimately enhances the patient's quality of life by enabling families to continue normal activities as much as possible. The care needs of patients on LTV are complex, therefore escalation and de-escalation (stepped-up and stepped-down) can present challenges as the patient moves through the pathway of care within hospital, between hospitals and between hospital and home.

There are particular problems with the "step-down" process, and this been highlighted as a priority by NHS England. There is thought to be considerable variation in the complex discharge pathway from hospital to home, and significant differences in the application of continuing care criteria and support packages available. Delays in organising and/or funding care in the community can result in patients and families experiencing delays in discharge from hospital. When discharged, insufficient staffing and training in the community can lead to gaps in overall care packages, case management, nursing support and continuity which are vital to ensuring patients' safety and quality of life. The training of health care professionals and parents is an essential part of the discharge pathway and can also lead to delays. Furthermore different funding streams are required to aid discharge and this again adds to the complexity of the discharge process, and can also add to delays. To better understand the difficulties involved in discharging children and young people home on LTV in organising their community care, the discharge and planning process must be reviewed.

In addition the long term trajectory of these young people may vary greatly. Survival has improved in many diagnostic groups with patients transitioning to adult care and living many years, others require escalation of ventilatory support over time stepping up to invasive ventilation, while in other patient groups care may be stepped down from invasive to non-invasive ventilation. Supportive care has an important role in the management of all young people on LTV, but identifying the need for end of life palliative care where relevant, is crucial in some children. Understanding how these staging points and transitions are managed is likely to determine longer term outcomes and quality of life for patients and families.

Guidelines and standards

- The West Midlands Quality Review Service (2015)
- Quality standards for the respiratory management of children with neuromuscular weakness (2014)
- Children on long term assisted ventilation at home Royal Brompton & Harefield (2011)
- Children who are long term ventilated pathfinder project (2014)
- From hospital to home (2005) Noyes & Lewis (Barnardo's)

⁸ R H Davies, A Difficult Case: Home ventilation of a child with motor and sensory neuropathy

⁹ Aday LA, Wegner DH. Home care for ventilator-assisted children: implications for the children, their families and health policy. *Children's Health Care* 1988; 17:112–20; Fields AI, Coble DH, Pollack MM, *et al*. Outcome of homecare for technology-dependent children: success of an independent, community based case management model. *Pediatr Pulmonol* 1991; 11:310–17.

¹⁰ NHS England, Long-term ventilation: Service Specifications

¹¹ Margolan H., Fraser J. and Lenton S., Parental experience of services when their child requires long-term ventilation. Implications for commissioning and providing services

- Core guidelines for the discharge home of the child on long term assisted ventilation in the UK (1998) Jardine & Wallis
- NHS England Service Specification Paediatric long term ventilation
- Guidelines on discharge from hospital of children and young people with high support needs (2010)
- Royal College of Paediatrics and Child Health produced Facing the Future: Standards for Acute General Paediatric Services (2015)
- NHS England, Paediatric Critical Care and Specialised Surgery in Children Review (2017)
- https://www.england.nhs.uk/wp-content/uploads/2017/06/paeds-review-demandcapacity-analysis.pdf
- Guidelines and Audit Implementation Network (GAIN) Audit of discharge of children on long term ventilation (2015)
- NTSP guidelines
- Children and Young People's Continuing Care Policy:
 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attac
 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attac
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- Department of Health, Children and young people's continuing care: A brief guide for young people and parents (2016)
- Department of Health, National Framework for Children and Young People's
 Continuing Care (2016)
 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attac
 hment data/file/499611/children s continuing care Fe 16.pdf
- Department of Children and Youth Affairs (Ireland), Children First: National Guidance for the Protection and Welfare of Children (2017) https://www.dcya.gov.ie/documents/publications/20171002ChildrenFirst2017.pdf

Aims and objectives

Overall aim:

To identify remediable factors in the care of patients who are receiving, or have received, long-term ventilation (LTV) before their 25th Birthday.

Objectives

Organisational

- To review the organisation of care of long-term ventilation services including; access
 to services and health care teams, case co-ordination (including both inpatient and
 outpatient care), the role of primary care, the urgent care pathway, support services
 (including psychological support services), access to equipment, the availability of
 allied health professional services, and the role of external providers and case
 managers, and community health/home care teams in care packages)
- To review the transfer process (escalation and de-escalation of care), and to determine the role of local secondary care providers when patients are admitted/readmitted
- To review the provision of, access to, communication and planning within, and the skill mix of multidisciplinary care teams and evidence of shared decision making with providers outside the LTV centre
- To review the networks of care for this group of young patients across different service providers and across all professional groups
- To review the organisation of transition between paediatric and adult services including the commissioning of adult services
- To examine organisational aspects of care including the use of local and national guidelines, protocols and service specifications
- To review training and delivery of long-term ventilation in hospitals and at home (including expected competences vs. demonstrated confidence, and the safety of tracheostomy care/supporting respiratory management) for staff and carers
- To understand and inform the future local and specialist commissioning for this complex care pathway

Clinical

- To identify remediable factors in the quality of care received and produce recommendations for improvement, such as the management of complications
- To describe the routine management, case diversity and complexity including multiple comorbidities
- To review the decision-making process (including delays to discharge and transfer, variation in risk management, the management of transitions in care, and the process of Multi-disciplinary Team (MDT) decision making prior to LTV)
- To review the informed consent process prior to initiating an LTV pathway (including tracheostomy insertion) and discussion of risk at stages thereafter e.g. prior to discharge from Paediatric Critical Care and/or hospital
- To review the appropriateness of the location of care (i.e. in hospital when children and young people should be at home and vice versa)
- To review communication between clinical teams
- To review safety aspects including routine patient and equipment monitoring and respiratory/tracheostomy care

- To identify whether the physical and psychosocial and emotional well-being needs of patients and families receiving LTV in hospital or at home are met, at each step of the pathway
- To determine what initial and ongoing training and support is available to parent carers
- To describe the urgent care pathway for patients already established on LTV
- To specifically review the clinical care provided during transition between paediatric and adult services, including delays, communication issues and leadership/ownership

Methods

Population/Inclusions

Data will be collected on patients up to their 25th birthday who are receiving, or have received, long-term ventilation.

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)'.

A nominated study contact will identify all patients receiving LTV under their service over a two year period from the 1st April 2016 to 31st March 2018 (method detailed below in case identification) and populate them in a Case Identifier Spreadsheet. Cases for inclusion in the peer review process will focus those patients who had an acute admission during the study period.

Although ventilation procedures are coded, the duration of ventilation and the intent to discharge home on ventilation is not, and therefore patients cannot be identified from hospital PAS systems. In addition to this, the aim is to assess all points in the pathway, not just new initiations. However, to assist with case identification, hospitals and services may find the following OPCS codes helpful in narrowing the pool of patients from which to identify those receiving LTV.

- E85.1 Invasive ventilation
- E85.2 Non-invasive ventilation
- E42.1 Permanent tracheostomy
- E42.3 Temporary tracheostomy
- E42.4 Revision of tracheostomy
- E42.5 Closure of tracheostomy
- E42.6 Replacement of tracheostomy tube
- E42.7 Removal of tracheostomy tube
- E42.8 Other specified
- E42.9 Unspecified

Exclusions

Patients discharged on home oxygen

Participating providers of healthcare

All hospitals and services where children, young people and young adults under the age of 25 years old on long-term ventilation (both invasive and non-invasive) may be cared for will be asked to participate in the study. These will include community and acute providers that

deliver critical care, respiratory services, long-term ventilation and step down services. This will include hospitals and services where:

- Long term ventilation is initiated
- Patients aged 0-25 receiving LTV are or could be care for (both acute and community)
- Emergency care is provided
- The hospital provides home ventilation

Incidence and prevalence

There are no specific figures on incidence or prevalence of this group due to the lack of coding of 'long-term'. It is only possible to understand the number of episodes according to national data (HES, PEDW, ISD and NISRA); in 2016/17 the following numbers of episodes of ventilation in children and young people aged 0-24 were identified.

Procedure	Н	ES	PEC	OW¹	NIS	RA ²	ISI	D*
	1°	All	1°	All	1°	All	1º	All
E42.1 Permanent tracheostomy	16	26	0	17	18	30		
E42.3 Temporary tracheostomy	153	584	4					
E42.4 Revision of tracheostomy	27	59	1					
E42.5 Closure of tracheostomy	12	26	0					
E42.6 Replacement of	277	829	4					
tracheostomy tube								
E42.7 Removal of tracheostomy	92	171	1					
tube								
E42.8 Other specified	23	42	0					
E42.9 Unspecified	5	9	1					
E85.1 Invasive ventilation	15382	21627	247	1583	1021	1469		
E85.2 Non-invasive ventilation	27128	38116	981					

^{1.} 3 digit OPCS code available only

Work undertaken as part of the review undertaken for the Paediatric Critical Care Clinical Reference Group estimated 80-100 new onset tracheostomy ventilated children annually. The review also identified the number of tracheostomy ventilated children managed out of hospital to be approximately 250-275, with a further 1000-1300 children dependent on non-invasive respiration. (NHS England Service Specification, Paediatric Long-Term Ventilation)

The patients for this study identified via the data collection spreadsheet will be used to collate numbers of patients receiving LTV, from which cases will be randomly sampled for inclusion in the study (further details in the 'Methods of data collection' section).

Method of data collection

There will be five separate main aspects of the study; these different data sources will not be linked:

- 1. Information about services available, clinical information and copies of selected case notes will be collected for peer review, to include:
 - Acute care, including PCC/HDU, Adult intensive care, respiratory services, LTV services, step down services
 - Community care

². 3 digit OPC code available only, 0-19 year olds

^{*} ISD data as yet unknown

- Short breaks/respite, hospices and palliative
- Pre-hospital care
- Primary care
- 2. Patient and parent carer views will be collected by NCEPOD through an on-line anonymous survey. We will work with Local Reporters, study contacts and patient groups (i.e. WellChild) to encourage involvement.
- 3. The National Children's Bureau will be commissioned to undertake patient and parent/carer focus groups and face-to-face interviews. In order to reach a number of parent carers, as well as arranging a number of fixed locations for the focus groups online focus groups will also be organised. No patient identifiable data will be collected and the data will not be linked to the NCEPOD clinical data collection. Data collected will include information on:
 - Education
 - Training
 - Community service provision
 - The commissioning of services

A separate communications strategy will outline the details of this.

- 4. Clinician and commissioner views will be collected through interviews and an anonymous online survey. We will work with Local Reporters and study contacts to encourage involvement from clinicians. NCEPOD has recruited a clinician to undertake interviews with professionals working with young people receiving long-term ventilation to gain an understanding of their views of service provision. To complement this a larger scale short on-line survey will be made available gain a wider understanding of the views of clinicians. Data collected will include the following information on:
 - The commissioning of services
 - Transition arrangements
 - Equipment
 - Training
- 5. Organisational survey

An organisational questionnaire will be sent to all hospitals and services where children and young people on long term ventilation may be cared for, (not just specialist centres) to collect data on the organisational aspects of care. Trusts/Health Boards will include both acute, community, and independent hospitals.

The table below summarises the data sources for significant points along the patient nathway.

Area of enquiry Method of data collection	Confidentiality
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Home	Interviews, supported by surveys and focus groups	Anonymous
Hospital doctors	Interviews, supported by surveys and focus groups	Anonymous
Outpatients appointments	Case notes, clinical questionnaire, organisational questionnaires	Identifiable
Inpatient care	Case notes, clinical questionnaire, organisational questionnaires	Identifiable
Urgent care pathway for patients established on LTV	Interviews, case notes, clinical questionnaire, organisational questionnaires	Identifiable
Community care	Case notes, clinical questionnaire, organisational questionnaires	Identifiable
Emergency services	Interviews, supported by surveys and focus groups	Anonymous
General practitioner	Case notes (communications with the GP included in the main case note data collection. GPs will not be contacted directly)	Identifiable
Hospice/respite	Patient & parent/carer, & clinician interviews	Anonymous
Commissioners	Interviews, supported by surveys and focus groups	Anonymous
Allied health professional care	Interviews, supported by surveys, case notes, clinical questionnaire, organisational questionnaires	Identifiable
Other services received (including education and social services)	Interviews, supported by surveys and focus groups	Anonymous

Sample Size

Sample Size								
Data source	Target number							
Online clinician survey	200							
Clinician and commissioner interviews	50 – 100							
Parent/carer & patient focus groups	30 - 60 / 18 - 30							
Parent/carer online survey	100 – 200							
Organisational questionnaire	~250							
Clinician questionnaires	~500							
Case note review	~200 – 250							

Case identification

As long-term ventilation is not coded, the following method of identifying patients has been will be undertaken:

Within each hospital NCEPOD has a Local Reporter (usually employed in clinical audit) who is responsible for providing the details of patients for inclusion. At the start of the study the Local Reporter will be contacted and sent details of the study criteria; at the same time the Local Reporter will be asked to set up a number of study contacts. It is anticipated study contacts will need to be in place in areas where:

- Long-term ventilation is initiated
- Patients receiving LTV are or could be cared for (both acute and community)

- Emergency care is provided
- The hospital provides home ventilation

Study contacts will need to be in place in both adult and paediatric services. Where multiple areas of care are in place within a site a study contact will be set up in each area with one primary contact in place who will be responsible for coordinating the study overall within the hospital.

This contact will be asked to populate a spreadsheet with the details of all patients who have been admitted to hospital or followed up by the hospital over the two year study period (both on the newly commenced and follow up pathways). Data collected will include the patient's identifiers (NHS/CHI number, hospital number, date of birth), month/year of ventilation (newly initiated or established), the type of ventilation (invasive/non-invasive), the date of the most recent acute hospital admission within the study period, the number of previous hospital admissions, the number of outpatient appointments attended, the details of the centres responsible for providing specialist LTV care and ongoing community care, the underlying diagnosis of the patient and the reason for LTV.

Once a comprehensive list of patients has been gathered a limited number of cases will be randomly sampled for inclusion in the clinical questionnaire and peer review process to ensure hospitals are not overburdened. Sampling will include the following groups:

- A group of patients newly initiated on invasive long-term ventilation (initiations between 1st April 2016 – 31st March 2018) – clinical questionnaire only
- A group of patients who are not admitted to hospital during the study period clinical questionnaire only
- A group of patients who have an acute admission to hospital during the study period
 clinical questionnaire and case note review

Study promotion

Prior to data collection, NCEPOD will contact all specialist long term ventilation services, the British Paediatric Respiratory Society, and the Home Mechanical Ventilation Network to promote the study. The study will also be promoted to parent/carers and patients via patient groups (NCB/WellChild and via their contacts), NCEPOD Local Reporters (sending the study poster on to the relevant departments both in the community, secondary and tertiary care), via study contacts recruited as part of the case identification strategy, and via the relevant Colleges and Associations.

Questionnaires

Clinician questionnaire

Four questionnaires will be used to collect data for this study:

- 1) Tracheostomy insertion questionnaire: A questionnaire will be sent to the named consultant responsible for undertaking the procedure (new tracheostomy insertions between 1^{st} April $2016 31^{st}$ March 2018).
- 2) Admission to hospital: A questionnaire will be sent to the named consultant responsible for the patient at the time of admission to hospital (where applicable).
- 3) Ongoing long-term ventilation care: A questionnaire will be sent to the named consultant responsible for initiating and providing ongoing long term ventilation (all patients).
- 4) (Main) Community nursing team: A questionnaire will be sent to the team responsible for providing the ongoing care to the patient in the community (all patients where applicable).

The clinical questionnaires will be sent to the NCEPOD Local Reporter for dissemination. Reminder letters will be sent at six weeks and ten weeks where the data is outstanding.

Clinicians will be asked to return copied extracts of the patients case notes to NCEPOD alongside the completed questionnaires (where applicable).

Case note review

Case note review will focus on the group of patients who had an acute admission during the study period (1^{st} April 2016 – 31^{st} March 2018). Where patients were transferred, data will be requested from both the initial admitting hospital and the subsequent admitting hospital.

Case notes

Notes relating to the acute admission will include:

- Clinical notes for the duration of the admission
- Operation notes and consent forms
- Nursing notes
- Emergency health care plans
- Discharge notes
- Community therapy notes
- Outpatient correspondence and clinic letters
- Allied health professional notes
- MDT summaries
- Referral letters
- Any other correspondence with the patient/parent/carer not listed above

Notes relating to the 6-month period prior to the acute admission:

- Clinic letters
- Discharge summaries

Upon receipt at NCEPOD the case notes will be redacted if not already done so prior to sending.

Organisational questionnaire

Data collected will include information around the organisation of services, networks of care and multidisciplinary team working, the commissioning of services, the use of guidelines and protocols and training.

Anonymous on-line parent carer survey

To be developed by NCEPOD with input from the National Children's Bureau (NCB) and WellChild. The on-line anonymous survey will be disseminated via the NCB networks, and also via the NCEPOD local reporters to send to the relevant departments in acute care and community care. The survey will not be linked to any other aspects of data collection. This survey will gather data on patient/parent carer views of the services available to them.

Anonymous on-line clinician survey

A questionnaire will be made available via the NCEPOD website for completion by all clinicians who may provide care for children and young people on LTV. This will gather data around the commissioning of services, training and risk management, other key areas for improvement and examples of excellence.

Reviewer assessment form

A multidisciplinary group of reviewers (details below) will be recruited to assess the case notes and questionnaires and give their opinions on the quality of care via the reviewer assessment form.

Study method test

The data collection methods and data collection tools will be tested to ensure they are robust.

Analysis and Review of Data

Reviewers

A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on the care the patients received. The reviewer group will comprise paediatricians and physicians (including representation from both acute and community care), respiratory physicians, intensivists/critical care practitioners, anaesthetists, nurses (including specialist long term ventilation nurses and community care nurses), speech & language therapists, physiotherapists, occupational therapists, for both paediatric and adult services.

An advert will be sent to Local Reporters to disseminate throughout the relevant departments. It will also be placed on the NCEPOD website. Successful applicants will be asked to attend a training day where they will each assess the same two cases to ensure consistent assessment. A number of meeting dates will be arranged, and each reviewer will then be asked to attend a further 6 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting from across the UK. Each meeting will be chaired by an NCEPOD clinical coordinator who will lead discussion around the cases under review. Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection

All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic identifiers and anonymise paper documents. Section 251 approval has been obtained to perform this study without the use of patient consent in England and Wales. Public Benefit Privacy Panel approval has been received for Scotland.

Dissemination

On completion of the study a report will be published and widely disseminated.

Data sharing

Post publication of the study there is the potential to share anonymised data sets with interested parties working in the same field. This will be undertaken following a strict process and will ensure the data does not become identifiable in their nature due to small numbers.

Additional resources

NCEPOD Communications Strategy for long-term ventilation 2018. Patient information poster.

Timescale

Timescale																						
	<u>≤</u>	Αp	M	Jur	Ju	Au	Se	0	Z	De	Ja	Fe	Z	Αp	Ma	Jur	Ju	Au	Se	0	No	De
	Mar 18	Apr 18	May 18	June 18	July 18	Aug 18	Sept 18	Oct 18	Nov 18	Dec 18	Jan 19	Feb 19	Mar 19	Apr 19	May 19	June 19	July 19	Aug 19	Sept 19	Oct 19	Nov 19	Dec 19
	 	8	∞	8	8	∞	∞	ω	∞	8		9	9	9	9	9	9	9	9	9	9	9
First meeting of																						
the study advisory																						
group																						
Write protocol																						
Collect																						
patient/parent																						
carer data																						
Design online																						
clinician																						
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interviews and																						
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questionnaire																						
Patient & clinician																						
data analysis																						
Second meeting of																						
the study advisory																						
group																						
Design the clinical																						
questionnaires																						
Test data																						
collection method																						
Design study																						
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Start clinical data																						
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Presentation to																						
SAG and reviewers																						
Produce final																						
report																						
Publish report and																						
disseminate																						
results																						