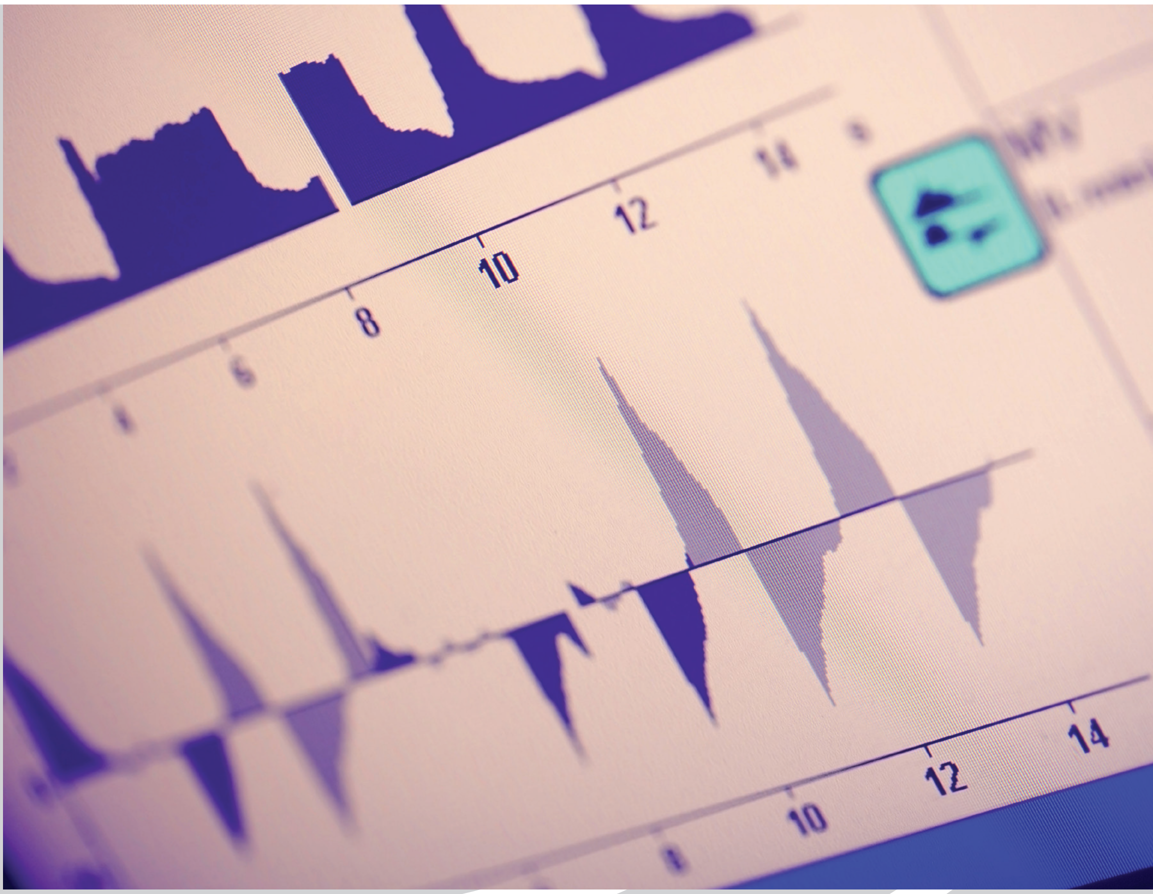
Balancing the Pressures

A review of the quality of care provided to children and young people aged 0-24 years who were receiving long-term ventilation



NCEPOD

Improving the quality of healthcare

Noah's Experience: an example of living as a young person on long-term ventilation

- Social Worker – Children with Disabilities Team
  - Benefits
    - Tax Credits
    - Carer's Allowance
    - Disability Living Allowance
    - Child Benefit
  - Direct Payments
    - Employment Tax
  - Charities to Help
- Commissioning
  - Agency
    - Carers
      - Recruiting/Training
  - Pathway Back into Hospital
    - Direct Ward Access
    - Staff/ Carers in Hospital
- Family/Play
- School
  - SENCO
  - Emergency Healthcare Plans
  - The Law
  - Educational Psychologist
- Child Mental Health
  - Disabilities Nursing Team
  - CAMHS
  - CHEWS Emotional Wellbeing
- Multidisciplinary Team
  - Respiratory Consultant
  - Neurology Consultant
  - LTV Team - Sleep Studies
  - Tracheostomy Nurse
  - Community Nurse
    - Bloods
    - Samples
  - GP
    - Prescribing Medications
      - Pharmacy
      - Special Prescriptions
        - Collecting from Various Places
          - Stock Control
- Child Development
  - Incontinence
    - Nappies
      - Reordering
  - Speech and Language Therapy
  - Physiotherapy
    - Exercises
  - Occupational Therapy
    - Order Equipment
- Equipment
  - Orthotics
    - Insoles
  - Maintenance
  - Oxygen
    - Reordering

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people aged 0-24 years who were receiving long-term ventilation

A report published by the National Confidential Enquiry into
Patient Outcome and Death (2020)

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Foreword

This study reviewed the quality and organisation of care provided to children and young people receiving long-term ventilation (LTV). The lack of an overarching procedure code, the numerous specialties involved in care delivery and the sparsity of centrally collected information, has meant that a variety of data collection methods were employed in order to gather the rich data presented here. Everyone involved, especially the NCEPOD Local Reporters and study contacts must be congratulated for identifying over 3,000 children and young people receiving LTV.

The report presents the opinions of service users, parent carers as well as healthcare professionals who have provided peer review of clinical cases, participated in focused interviews and responded in large numbers to online questionnaires about the LTV services they receive or provide. This brings together a very broad set of opinions and information about the overall quality of care provided to children and young people receiving LTV.

Unlike the majority of NCEPOD reports, in which we are able to present remediable factors in care along a simple patient pathway from admission to discharge, this report has been presented by the themes which arose from detailed interviews and surveys of experts – the service users, their families and their care teams. We have chosen to present our findings thematically to complement the existing national work on pathways and to ensure that the key messages from service users, families and their care teams are heard and acted on. Chapter 3 in particular highlights the complexity and variability of LTV pathways and organisation of services experienced by this group of people. Similarly, Chapter 5 highlights issues in the importance of ensuring that acute patients are subsequently admitted to hospitals in which LTV is fully understood (many of these admissions are unplanned).

It was notable that there were particular parallels between this study and that of the recent NCEPOD report reviewing chronic neurodisability.[1] In both studies, people were highly dependent on more complex treatment modalities, reliant on a large multidisciplinary team which stretched across many provider organisations and experienced issues in the transition from child to adult services.

Development and availability of life-saving and life-sustaining technologies in the last 20-30 years has transformed the care for children and young people requiring LTV. People who would rarely have survived beyond childhood are now arriving in adult services and this has not been anticipated until recent years. Since children and young people are cared for by several specialities, and a major part of their care delivered in the community, they have been much less visible as a defined population.

Thirty years ago it would have been virtually impossible to discharge a child from a hospital intensive care or high dependency setting to the community, or home, whilst still requiring ventilator support. Knowledge, technology and attitudes have changed, and as this population has grown, so has the understanding of their situation and many related issues. The number of people requiring LTV will continue to grow and it is therefore timely to take a long hard look at the care provided to this group and consider how we can collectively anticipate their needs and do better.

Whilst there are elements of clinical care that were highlighted for improvement throughout the study, the strongest message in this report, for me, was the lack of co-ordination and inconsistent standards of commissioned care. I hope that this study will bring LTV into sharp focus, and stimulate those responsible for commissioning and delivering care pathways across all healthcare sectors to establish and standardise best practice. Many examples of good practice are to be found within this report and excellent national standards from the Quality Review Service (formally West Midlands Quality Review Service)[16] and international guidance from the Canadian Thoracic Society[44] exist which underpin the ideal care pathway for this group of patients.

As ever I must thank all those involved in undertaking this study, which represents an enormous combined effort. It is once again gratifying to see contributions to the review process from such a wide ranging, multidisciplinary group of healthcare professionals and in particular children and young people on LTV and their parent carers. Our Local Reporters and study contacts are pivotal in identifying cases and supporting the return of notes and questionnaires and without them our studies would simply not happen. As ever our Steering Group have provided valuable commentary and advice to the Clinical Co-ordinators and NCEPOD staff who ultimately compile the report. On behalf of the Trustees I would like to thank all involved for producing this most important report.

Ian C Martin,
Chair

Introduction

What is long-term ventilation?

Long-term ventilation (LTV) refers to various types of respiratory support provided every day for a period of at least three months.[2] Ventilation is delivered either via a tracheostomy tube (invasive) or via a face mask or nasal cannula (non-invasive). The aim of LTV is to improve survival and quality of life in people with conditions that have led to respiratory failure. It generally involves applying two levels of pressure, one on breathing in and one on breathing out (bilevel positive airway pressure ventilation), although continuous positive airway pressure, commonly known as CPAP might also be used, often to overcome upper airway obstruction.

To date the actual number of people receiving LTV in the UK is not known, as there is currently limited local or national data collection, and no national procedure code for LTV. Where data have been published, it shows that the number of children and young people reported to be receiving LTV in the UK increased from one in 1975 to almost 1,400 in 2013.[3] This is considerably lower than the number identified in this study, and which was still believed to be an underestimate.

The LTV population ranges from small, often premature, babies, requiring support for lung, airway or central nervous system problems they were born with, to older children and young people with failing respiratory or neuromuscular function. Whilst people on LTV often have multiple comorbidities and/or life-limiting conditions, their overall survival has improved and now more people transition from child to adult services and are living for many years.[4,5]

Advances in ventilator technology, and improved familiarity with the concept of delivering care at home may have helped to make the decision to initiate LTV easier, but delivering this relatively complex care, particularly outside of a hospital setting, has remained a challenge.

How are LTV services designed?

The organisation of LTV services varies widely across the UK, this can be seen in Chapter 3. LTV (both paediatric and adult) is generally initiated in hospital.[6] There are a small number of hospitals in which LTV care is co-ordinated, but no standard definition of what this entails is available, therefore the exact number of hospitals that would be classified as 'LTV centres' was unknown at the start of the study. Therefore, NCEPOD defined LTV centres as 'a centre in which people were provided with the normal decision-making, support and review of their ventilator care', and those responding to the organisational questionnaires were asked to self-report whether their hospital came under that definition. Similarly there are no published numbers or definitions as to what constitutes a 'community LTV service'.

The number of critical care units was better defined, with 27 paediatric critical care units and approximately 250 adult critical care units across the UK. However, whilst the Quality Review Service Quality Standards state *"Tertiary long-term ventilation services should be based on the same hospital site as a paediatric critical care unit (if initiating invasive ventilation) or a paediatric high dependency unit (if initiating non-invasive ventilation only)"*[16] there is no equivalent guideline for adults receiving LTV.

What are the issues in providing LTV?

The issues related to the provision on LTV vary, as the range of ventilator support required varies from person to person. Some people require overnight non-invasive ventilation only, whilst others are unable to breathe at all without a ventilator, and may require a tracheostomy tube to connect to it (this group generally has more complex challenges, with more potentially serious complications).

Provision of care outside of a hospital setting, in particular for people with a tracheostomy, often requires adaptation of the home environment, and complex care packages. Inconsistencies in the care packages offered to families have been reported.[3] Despite these challenges, it is widely accepted that people on LTV and their families benefit enormously from being at home rather than prolonged stays in hospital. Children who spend extended periods of time in a hospital setting have been shown to experience developmental and psychological challenges, moreover many caregivers express a preference for home care.[7-9]

Some people may require escalation of ventilator support over time, 'stepping-up' from non-invasive to invasive ventilation. Conversely others may be 'stepped-down' from invasive to non-invasive ventilation. The knowledge and skills to deliver this treatment has implications for the organisation of LTV services as well as for training for those involved, both in the community and in all hospitals to which people may present, not just LTV centres.

Discharge arrangements have been highlighted as a key area in a recent systematic review of the experiences of children and young people living with respiratory assistance.[10] Poor discharge planning was reported to lead to insufficient community staffing and training. This led to gaps in overall care packages, nursing support and continuity of care. The training of healthcare professionals and parent carers is therefore an essential part of the discharge pathway. Often different funding streams required to plan and co-ordinate discharge added to the complexity of the process. Published work has also highlighted that as well as socio-economic factors, accessing short break/respite care is an issue facing those who care for children and young people on LTV.[11]

However, it is not all negative. An ethical framework which supports the decision-making process for LTV has been proposed.[12] This is a positive move for people on LTV, their families and the healthcare professionals caring for them, as it will help ensure that life-changing decisions are centred around the person's best interests.

This report should be used to support improvements in the clinical care and organisation of LTV services in conjunction with existing guidelines and service specifications.

Executive summary

Aim

The aim of the study was to identify remediable factors in the care provided to people who were receiving, or had received, long-term ventilation (LTV) up to their 25th birthday.

Method

Data were collected from a number of sources to achieve an overall view of the care provided to this group. Data presented in the report highlights: the number of people identified on LTV during the study period; the clinical care provided to a subgroup of people on LTV; the organisation of LTV services; the views of service users, parent carers and health and social care professionals providing the care.

Key messages

The five key messages listed here, agreed as the primary focus for action, have been derived from 12 recommendations (see pages 11-14 and Appendix 1).

1. SERVICE PLANNING AND COMMISSIONING OF INTEGRATED CARE

Formalisation of the service planning and commissioning of LTV services through an integrated network of care providers is required. The aim would be to reduce variability in access to areas such as therapy services in and out of hospital, facilitate discharge, enable respite care and simplify how ventilator equipment is purchased and serviced.

2. MULTIDISCIPLINARY CARE

Improved access to an appropriate multidisciplinary care team is needed to ensure people on LTV and their parent carers can be supported in the community as well as during an admission to hospital.

3. EMERGENCY HEALTHCARE PLANS

Templates for Emergency Healthcare Plans should be developed and standardised for people receiving LTV. They should provide information about what to do and who to contact in an emergency situation. They should form part of hand-held records that are fully accessible to the person receiving LTV, parent carers and the health and social care teams.

4. DISCHARGE PLANNING

Active discharge planning should start at the point of an admission and include all relevant members of the integrated care network to enable a prompt and safe discharge home or to other community services. The discharge plan should reflect any changes in respiratory care.

5. TRANSITION FROM CHILD TO ADULT SERVICES

Transition planning should minimise disruption and prepare for any necessary changes that will occur. Effective leadership for planning transition of care should be encouraged to ensure children access adult LTV services easily. There should be no gap in the provision of LTV care.

Recommendations

These recommendations have been formed by a consensus exercise including all those listed in the acknowledgements. See Appendix 1 for how the key findings in the report support the recommendations.

The recommendations highlight a number of areas that are suitable for regular local clinical audit and quality improvement initiatives by services providing LTV care, to address any areas of care that are below the expected standard. The result of local audits or quality improvement initiatives should be presented at quality or governance meetings. Action plans to improve LTV care should be shared with Executive Boards. The learning applies to all hospitals in which people receiving LTV might be cared for, not just LTV centres.

<table>
<tr><td colspan="2">Suggested target audiences to action the recommendations are listed in italics under each one. The primary target audience/audiences are in bold.
<i>The term ‘healthcare professionals’ includes, but is not limited to, doctors, surgeons, nurses, general practitioners, physiotherapists, speech and language therapists and occupational therapists</i></td></tr>
<tr><td colspan="2">RECOMMENDATIONS RELATED TO SERVICE PLANNING AND COMMISSIONING</td></tr>
<tr><td>1</td><td>Ensure service planning/commissioning of integrated care pathways for long-term ventilation services includes formal contract arrangements and local standardisation where possible.
These arrangements should bridge child and adult health as well as social care services, respite care and any other partnerships relevant to the local network. Networks should map commissioning arrangements to ensure integration and consistent standards of care and national commissioners should provide a forum to ensure that long-term ventilation provision is considered collectively and delivered to agreed standards.

<i>Target audiences</i>
<i>Service Planners/Commissioners (National and Local)</i> <i>with support from Trust/Health Board Executive Committees, Social Care, Primary Care, Education, Respite/Hospice Care, Healthcare Professionals in all hospitals (including those that are not LTV centres) and Third Sector Organisations</i></td></tr>
<tr><td>2</td><td>Ensure that it is possible to identify all people who are receiving long-term ventilation.
a) Locally this should be achieved by implementing/maintaining a database as soon as possible
b) Nationally this should be achieved by developing procedure codes for long-term ventilation to bring together the local data collection and support a national database to quantify service provision and facilitate quality improvement

<i>Target audiences</i>
<i>LTV Services and NHS Digital, NHS England, NHS Improvement, NHS Scotland, NHS Wales Informatics Service, Northern Ireland Statistics and Research Agency</i> <i>with support from Trust/Health Board Executive Committees, Social Care and Service Planners/Commissioners</i></td></tr>
</table>

3	**Ensure efficient care planning and discharge by providing a multidisciplinary team as part of an integrated care pathway.** This team should work across community and hospital networks of care for child and adult long-term ventilation services, have an identified clinical lead and include as a minimum: a) Medical and nursing staff b) Physiotherapy c) Speech and language therapy d) Psychology Where applicable e) A specialist in tracheostomy care f) Palliative care/hospice care g) Local service planners/commissioners ***Target audiences*** ***Service Planners/Commissioners and Trust/Health Board Executive Committees*** *with support from LTV Services, Social Care and Hospice/Respite Care, Psychology and Palliative Care*
4	**Undertake shared decision-making at the point of long-term ventilation initiation, particularly if it is likely to be a life-long therapy.** The decision-making process should include input at all stages from: a) Children and young people (where ever possible) b) Parent carers c) The multidisciplinary team (MDT) listed in Recommendation 3 d) The person's general practitioner whenever practical/possible e) Palliative care when appropriate The process* should also include: f) Discussions over a period of time to ensure decisions are thoroughly considered g) Input from independent healthcare professionals for peer review/mediation as required h) Provision of approved written and/or online information i) Support from other families with a child on long-term ventilation should be considered **A nationally agreed decision-making and ethical framework for long-term ventilation care as proposed by Ray et al should be considered to aid the process. This should involve children, young people and their families as key partners in any development* Ray S et al. 2018. Towards developing an ethical framework for decision-making in LTV in children. Archives of Disease in Childhood. 103(11): 1080–1084 ***Target audiences*** ***Children and Young People, Families, Service Planners/Commissioners and Trust/Health Board Executive Committees*** *with support from LTV Services, Social Care and Hospice/Respite Care, General Practice, Palliative Care, Medical and Surgical Royal Colleges, Clinical Networks, NHS England and the Departments of Health in the Welsh, Scottish and Northern Ireland Governments*

5	**Ensure that the planning for transition from child to adult services, including the provision of joint transition clinics, has clearly identifiable clinical and executive leadership and forms part of an integrated care pathway for people on long-term ventilation.** Developmentally appropriate and patient-centred transition planning should commence at the latest by the age of 14 years* **This supports NICE Guideline (NG43)* ***Target audiences*** ***Children and Young People, Families, LTV services and Trust/Health Board Executive Committees*** *with support from Clinical Directors, Healthcare Professionals in all hospitals (including those that are not LTV centres), Social Care, Primary Care and Service Planners/Commissioners*
6	**Provide a structured training programme and associated resources for long-term ventilation which prepares:** a) People on LTV and parent carers for home care b) Community providers for routine care c) Non-specialist clinicians for hospital admissions ***Target audiences*** ***Health Education England, NHS Education for Scotland, Health Education and Improvement Wales and Department of Health Northern Ireland*** *with support from, Children and Young People, Families, LTV Services, Medical and Surgical Royal Colleges, Specialty Associations, Service Planners/Commissioners and Third Sector Organisations*
7	**Standardise arrangements for long-term ventilation equipment including:** a) Purchasing b) Servicing c) Consumables ***Target audiences*** ***Service Planners/Commissioners and LTV Services***

RECOMMENDATIONS RELATED TO ROUTINE CARE

The following five recommendations are aimed at facilitating care wherever it is delivered and recognising that people receiving LTV can present to any hospital as an emergency. Service planners/commissioners, all hospitals (including those that are not LTV centres) and Clinical Networks should recognise this in terms of their preparedness for such episodes and in the decision-making about the most appropriate location for care.

8	**Standardise templates for personalised Emergency Healthcare Plans for all people on long-term ventilation.** They should: a) Be easily accessible by all members of the care team b) Be clearly laid out so that information can be easily recognised by all members of the care team c) Be reviewed at least annually, and after every hospital admission, by the clinical team and the service user/parent carer d) Form part of any hand-held records e) Include a fast-track admission plan ***Target audiences*** ***LTV Services*** *with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Service Users and Third Sector Organisations*

9	**Ensure all people on long-term ventilation have access to age appropriate emergency care** by a team with the relevant competencies, regardless of location. ***Target audiences*** ***Trust/Health Board Executive Committees*** *with support from LTV Services, Emergency Care, Ambulance Trusts, Critical Care Services and Healthcare Professionals in all hospitals (including those that are not LTV centres)*
10	**Ensure good ventilation care when people on long-term ventilation are admitted to hospital for any reason by:** a) Undertaking a standard clinical and respiratory assessment b) Undertaking routine vital signs monitoring which includes, as a minimum, respiration rate and oxygen saturation c) Involving the usual LTV team if not admitted under their care d) Identifying clinical leadership of ventilation care ***Target audiences*** ***Healthcare Professionals in all hospitals (including those that are not LTV centres)*** *with support from Respiratory Clinicians, LTV Services and Critical Care Services*
11	**Ensure high quality discharge arrangements for people established on long-term ventilation who are admitted to hospital.** Planning should: a) Commence on admission b) Be clearly documented in the case notes c) Include the community and usual LTV team d) Document any actual or anticipated changes to respiratory care ***Target audiences*** ***LTV Services*** *with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Primary Care and Social Care*
12	**Optimise the frequency of clinical review on an individual basis, for those on long-term ventilation who are at an increased risk of admission*** **including people established on LTV < 2 years and those who have had an unplanned admission in the previous 6 months* ***Target audiences*** ***LTV Services*** *with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Primary Care and Social Care*

1

Method and data returns

Study Advisory Group (SAG)

A multidisciplinary group of clinicians specialised in: respiratory medicine (paediatric and adult), paediatric medicine, critical care medicine (paediatric and adult), anaesthetics (paediatric and adult), nursing, speech and language therapy, occupational therapy, physiotherapy, community nursing, community paediatrics, hospice services, otorhinolaryngology, psychology, commissioning organisations and lay/service user representatives, steered the study from design to completion.

Study aim

To identify remediable factors in the care of people who were receiving, or had received, long-term ventilation (LTV) before their 25th birthday.

Objectives

The SAG identified a number of objectives to address the primary aim of the study, which included, but were not limited to:

- The quality of care received
- Multidisciplinary care
- The decision-making and consent processes
- The appropriateness of the location of care
- Communication
- The clinical care provided at transition to adult services
- The organisation of services
- The transfer process within and between hospitals
- Clinical networks of care
- The use of local and national guidelines, protocols and service specifications
- Training for staff and parent carers

Notes related to the data collected

- Data were collected from a number of sources to achieve an overview of the care provided to people receiving LTV
- Data presented in the report summarise the findings from five different data sources to produce the narrative. This means that denominators throughout the report change according to the data source and to the number of responses to particular data items
- Consistent colour coding of data sources throughout the reports headings, figures and speech bubbles, have been used for ease of reference
    1. **PINK** relates to the large dataset of people identified as receiving LTV
    2. **ORANGE** relates to the subgroups of patients selected for in-depth clinical review using questionnaires to clinicians and peer review of case notes
    3. **BROWN** relates to the organisational data collected from hospitals in which patients on LTV are cared for, both acute and community care
    4. **BLUE** relates to the data collected from service users and parent carers via an online survey and face-to-face focus groups
    5. **GREEN** relates to the data collected from health and social care professionals via an online survey and one-to-one interviews
- Data from the surveys, focus groups and interviews were not linked to the data collected on individuals as part of the study population or the clinical peer review process

Data collected

1. Number of children and young people on LTV during the study

The number of people receiving long-term ventilation (LTV) is not information that has been collected centrally before, as there is no Classification of Interventions and Procedures (OPCS) code for LTV, and the way hospitals record the details of people on LTV varies.

In order to identify a study population, the NCEPOD Local Reporters (a named contact in every hospital) were asked to set up study contacts within their hospital. Between them, they collated the details of all people who were either under the care of their LTV service, or who were admitted to their hospital over the two-year study data collection period - 1st April 2016 to 31st March 2018 inclusive.

2. Sampled study population for the clinical peer review process

From the whole study population three groups were sampled for more detailed review:

1. *People who were already established on LTV* who had an acute admission to hospital: up to four people were sampled - two receiving invasive ventilation and two receiving non-invasive ventilation, with a length of stay of ≥1 day
2. *People who were established on LTV* who did not have an acute admission to hospital: up to five people were sampled - two receiving invasive ventilation and three receiving non-invasive ventilation

NB: For either group the number of people receiving non-invasive ventilation was increased if there were not enough people receiving invasive ventilation to include.

3. New tracheostomy insertion: up to five people per hospital who had a tracheostomy inserted between the 1st April 2016 – 31st March 2018

Sampling was undertaken once a majority of the data had been returned to ensure the same person was not sampled multiple times, in multiple groups. Following the strategy above this sampling resulted in a total of 463 (386 people already established on LTV, and 77 people who underwent a new tracheostomy insertion.

Coverage

Data were requested from NHS hospitals in England, Scotland, Wales and Northern Ireland as well as public hospitals on the Isle of Man, Guernsey and Jersey (see Appendix 3).

Data sources

Questionnaires

To gather data for this part of the study, up to four clinician questionnaires, per hospital, were disseminated to clinicians via the network of NCEPOD Local Reporters:

1. Lead clinician (ongoing care) questionnaire
This was sent to the team responsible for providing the ongoing ventilator care to the person on LTV regardless of whether they had an admission to hospital or not. Information was requested on the type of ventilation received, the level of dependency on ventilation, equipment, community care arrangements, outpatient reviews, transition to adult services, and overall care.

2. Acute admission questionnaire
This was sent to the consultant caring for the person on LTV at the time of their most recent acute admission. If the person was identified as being transferred to or from another hospital for acute care, an admission questionnaire was also sent for this admission. Information was requested on the reason for admission, the level of dependency on ventilation, previous admissions, transfers, adverse events, ongoing care during the admission and discharge.

3. Community team clinical questionnaire
This was sent to the team responsible for providing the ongoing community LTV care. Information was requested on the type of ventilation received, the level of dependency on ventilation, community care arrangements, equipment, training, emergency healthcare planning, the provision of other support services, commissioning and care plans, transition to adult services and overall care.

4. Tracheostomy insertion questionnaire
This was sent for completion by a clinician in the team involved in caring for the person on LTV at the time of the tracheostomy insertion. Information was requested on the condition of the person prior to insertion, the anticipated level of dependency, initial after care, consent, decision-making, ongoing care and discharge.

Case notes

Copies of case note extracts were requested for each person included in the sample who had an acute admission to hospital during the study period. These included:

- Clinical notes for the duration of the admission
- Nursing notes
- Emergency healthcare plans
- Operation notes and consent forms
- Community therapy notes
- Discharge notes
- Allied health professional notes
- Outpatient correspondence and clinic letters
- Referral letters
- Multidisciplinary team summaries
- Clinic letters and discharge summaries
- Any other correspondence relating to the 6-month period prior to the acute admission

Peer review of the clinical questionnaires and case notes

A multidisciplinary group of case reviewers was recruited to peer review the case notes and associated clinician questionnaires. The group of case reviewers comprised consultants, trainees and allied health professional specialists from acute and community care in the following specialties: respiratory medicine (paediatric and adult), paediatric medicine, critical care medicine (paediatric and adult), nursing, speech and language therapy, physiotherapy, occupational therapy, primary care and spinal medicine.

Questionnaires and case notes were anonymised by the non-clinical staff at NCEPOD. All personal identifiers were removed. Neither the Clinical Co-ordinators at NCEPOD, nor the case reviewers, had access to person identifiable information.

After being anonymised, each set of case notes was reviewed by at least one case reviewer within a small multidisciplinary group. At regular intervals throughout the meeting the Chair allowed a period of discussion for each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for discussion.

Case reviewers answered a number of specific questions using a semi-structured electronic questionnaire and were encouraged to enter free-text commentary at various points.

3. Organisational data

Two organisational questionnaires were disseminated via the network of Local Reporters, to collect data for this part of the study.

Only acute Trusts/Health Boards from which clinical data had been returned were sent two organisational questionnaires to be completed at a hospital level; one to be completed for child services (where applicable), and one for adult services (where applicable).

Community Trusts/Health Boards were sent two organisational questionnaires to be completed at a Trust/Board level; one to be completed for child services (where applicable), and one for adult services (where applicable). Questionnaires were only sent to community services that had been identified as being involved in the care.

4. Service user and parent carer online survey and focus groups

Service user and parent carer data were collected via an online survey and through interactive focus groups and qualitative interviews. The focus groups were undertaken by the National Children's Bureau (NCB).

Online survey

The survey was designed to gather the views of people on LTV and parent carers. A link was sent to a wide group of stakeholders to disseminate via their local and national service user and parent carer networks.

Focus groups

Recruitment for the focus groups was undertaken through the National Children's Bureau, NCEPOD and WellChild networks with a combined reach across the UK. The support from WellChild proved particularly helpful due to the day-to day contact LTV nurses had with families.

There were significant challenges with the recruitment of people on LTV and parent carers for the focus groups. Even when participation was arranged they had to cancel because of hospital admissions, absent carers, or other unforeseen circumstances. Children and young people proved even more difficult to reach. Small sizes for the focus groups meant that the resulting findings were likely to be less representative of the larger population. Nevertheless, the findings were consistent with those responding to the online survey.

5. Health and social care professional online survey and interviews

Online survey

An online link to this survey was sent to a wide network of study contacts to disseminate further via email and social media within their organisations and to any relevant networks they had, including Ambulance Trusts and Clinical Commissioning Groups.

Interviews

A series of interviews with healthcare professionals was undertaken to gather more in-depth views. Interviewees were selected from those who had indicated their willingness to be contacted by leaving their name and email address on the survey. The interviews focused on things that went well and did not go well with regard to service provision, equipment, commissioning, ventilation and safety.

Data returned

1. Number of children and young people on LTV during the study

It was reported from 113 hospitals within 94 Trusts/Health Boards that 3,061 people were known to be on LTV during the study period, although this is likely to be an under-representation due to the absence of coding for LTV, which means there is no way of easily identifying these patients, particularly those who are at home or who have transitioned to adult services (Figure 1.1).

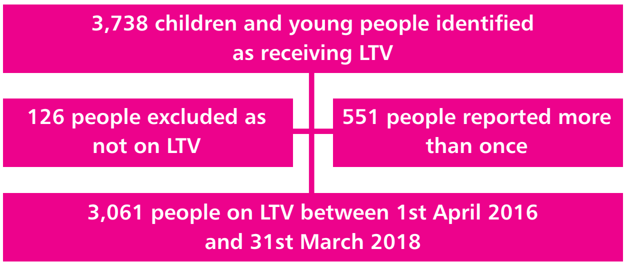


Figure 1.1. Data returned for the total study population of people on long-term ventilation

Age and sex

Where age was recorded, 688/2,980 (23.1%) people on LTV were between the ages of 14-18 years (therefore approaching transition to adult services - see Chapters 2 and 3).

Where both age and sex were recorded, 1,502/2,502 (60.0%) people were reported to be male, with an average age of 12 years and 1,000/2,502 (40.0%) were female with an average age of 11 years (Figure 1.2).

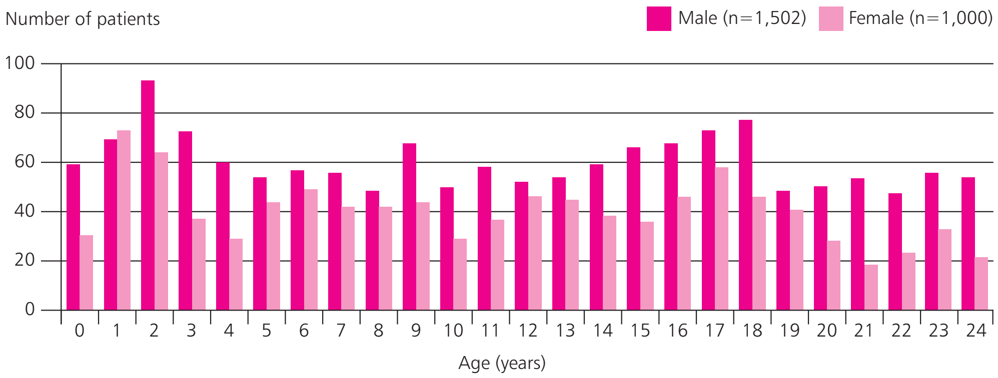


Figure 1.2 Age distribution by sex for the total study population (where both age and sex were available)

Type of ventilation used

Table 1.1 shows that 475/2,190 (21.7%) people were known to be on invasive ventilation during the study period and 1,677/2,190 (76.6%) people on non-invasive ventilation. This changed very little over the study period.

Figure 1.3 shows the age at which LTV was initiated, with an average age of 7.1 years for people initiated on invasive ventilation and an average age of 12.4 years for those on non-invasive ventilation.

Table 1.1 Type of ventilation received for the total study population

	Type of ventilation at initiation		Type of ventilation at 31/03/2018	
	Number of people	**%**	**Number of people**	**%**
Non-invasive bilevel positive airway pressure	959	43.8	1,059	38.6
Non-invasive continuous positive airway pressure	597	27.3	771	28.1
Invasive ventilation (tracheostomy)	330	15.1	345	12.6
Non-invasive ventilation (type not specified)	121	5.5	278	10.1
Invasive continuous positive airway pressure via a tracheostomy	96	4.4	83	3.0
Invasive ventilation (type not specified)	49	2.2	17	<1
Other	38	1.7	191	7.0
Subtotal	**2,190**		**2,744**	
Not answered	871		317	
Total	**3,061**		**3,061**	

**NB 3,061 is likely to under-represent the actual number of people receiving LTV due to the absence of national codes for LTV*

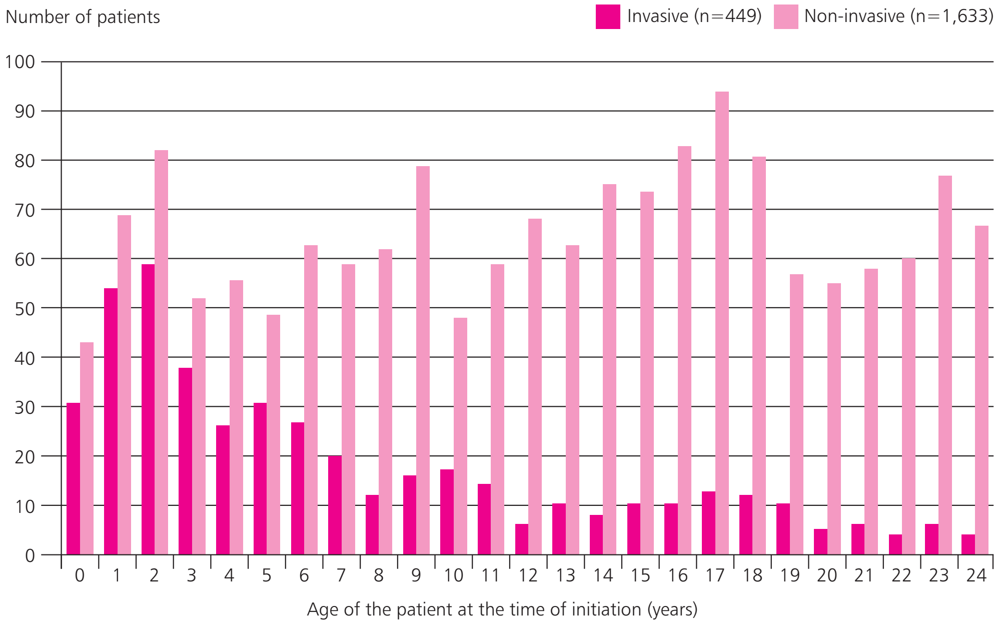


Figure 1.3 Type of ventilation received for the total study population by age at initiation (age was not provided for 26 people receiving invasive ventilation and 44 receiving non-invasive ventilation)

Underlying condition

The underlying conditions experienced by people on LTV were grouped into five categories as shown in Table 1.2.

Table 1.2 Underlying conditions of the total study populations

	Number of people	%
Upper airway obstruction/obesity	791	30.9
Musculoskeletal disorders	751	29.4
Disorders of the central nervous system	630	24.6
Chronic respiratory disease	227	8.9
Other	157	6.1
Subtotal	**2,556**	
Not answered	505	
Total	**3,061**	

**NB 3,061 is likely to under-represent the actual number of people receiving LTV due to the absence of national codes for LTV*

- The most frequent underlying conditions in people with an upper airway obstruction were obstructive sleep apnoea (164/791; 20.7%) and Down's syndrome (145/791; 18.3%)
- The most common conditions in people with a musculoskeletal disorder were muscular dystrophy (313/751; 41.7%)
- The most common conditions in people with a disorder of the central nervous system were cerebral palsy (96/630; 15.2%) and congenital central hypoventilation syndrome (64/630 (10.2%)
- Within the group of people with a chronic respiratory disease, 78/227 (34.4%) related to prematurity at birth

Duration of daily ventilation

A majority of people received ventilation overnight (Table 1.3). The most common group within the 'overnight and other' were those where ventilation was used overnight and for naps.

Table 1.3 Duration of daily ventilation of the total study population

	Number of people	%
Overnight	1,279	69.1
24 hours	301	16.3
Overnight and other	115	6.2
Other	157	8.5
Subtotal	**1,852**	
Not answered	1,209	
Total	**3,061**	

**NB 3,061 is likely to under-represent the actual number of people receiving LTV due to the absence of national codes for LTV*

Admission to hospital

An acute admission to hospital during the study period occurred in 1,710/2,999 (57.0%) people (Table 1.4). This is covered in more detail in Chapter 5.

Table 1.4 Acute admissions to hospital during the study period for the total study population

	Number of people	%
Had an admission during the study period	1,710	57.0
Did not have an admission	1,289	43.0
Subtotal	**2,999**	
Had an admission but the date given was outside the study period	62	
Total	**3,061**	

**NB 3,061 is likely to under-represent the actual number of people receiving LTV due to the absence of national codes for LTV*

2. Sampled study population for the clinical peer review process

Figure 1.4 summarises the number of people included in the in-depth review of clinical care, and the number of questionnaires/case notes returned.

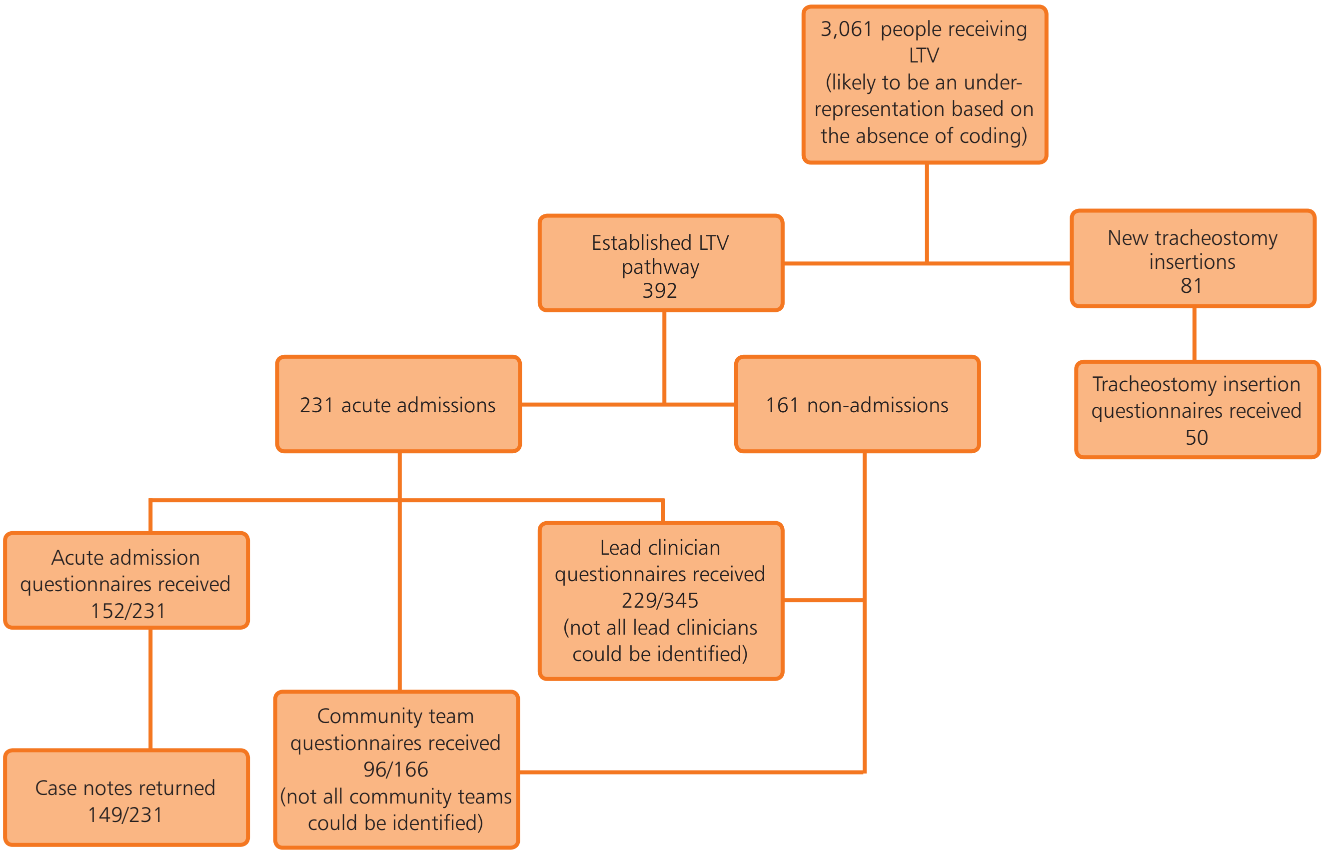


Figure 1.4 Study sample for inclusion in the clinical questionnaire and peer review

Table 1.5 Age of included study population by clinical data source

	Lead clinician questionnaire		Acute admission questionnaire		Community team clinical questionnaire		Tracheostomy insertion questionnaire		Case reviewer data	
	Number of people	%	Number of people	%	Number of people	%	Number of people	%	Number of people	%
<18 years	132	60.3	107	71.3	80	84.2	49	98.0	104	71.7
≥18 years	87	39.7	43	28.7	15	15.8	1	2.0	41	28.3
Subtotal	**219**		**150**		**95**		**50**		**145**	
Unknown	10		2		1		0		4	
Total	**229**		**152**		**96**		**50**		**149**	

Table 1.6 Type of ventilation being received by clinical data source

	Lead clinician questionnaire		Acute admission questionnaire		Community team clinical questionnaire		Case reviewer data	
	Type of ventilation as of 31/03/2018		Type of ventilation prior to admission		Type of ventilation as of 31/03/2018		At the time of admission	
	Number of people	%	Number of people	%	Number of people	%	Number of people	%
Invasive	61	26.9	49	34.8	43	45.3	52	35.4
Non-invasive	151	66.5	92	65.2	52	54.7	95	64.6
Other	15	6.6	0	0	0	0	0	0
Subtotal	**227**		**141**		**95**		**147**	
Unknown	2		11		1		2	
Total	**229**		**152**		**96**		**149**	

Tables 1.5 and 1.6 show the number of questionnaires retuned, by age and type of ventilation used. Very few people aged ≥18 years were sampled for inclusion in the tracheostomy insertion group, despite sampling being biased to include those who were receiving invasive ventilation.

3. Organisational data

Organisational questionnaires were received from acute hospitals and community services. Community services were only requested to complete a questionnaire if spreadsheet data had been returned, or when they had been identified as being involved in the care by the acute hospital, which is why the number included is smaller.

Care was most commonly provided in district general hospitals (Table 1.7). Table 1.8 shows the type of organisation participating and whether they were self-classified as an LTV centre. The number of hospitals defined as LTV centres varied depending on the question, and what LTV services were provided. As the majority of the organisational data were only returned from where LTV care was provided, the organisational data presented is weighted towards hospitals defined as LTV centres. Tables 1.9 and 1.10 show where care was provided by the type of ventilation provided.

Table 1.7 Age of the LTV population by type of hospital

	<18 years of age		≥18 years of age	
	Number of hospitals	**%**	**Number of hospitals**	**%**
District general hospital <500 beds	19	27.1	19	27.1
District general hospital ≥500 beds	21	30.0	18	25.7
Specialist paediatric tertiary centre	15	21.4	1	1.4
University teaching hospital	13	18.6	30	42.9
Other	2	2.9	2	2.9
Total	**70**		**70**	

Organisational data

Table 1.8 Type of centres

	<18 years of age		≥18 years of age	
	Number of hospitals	**%**	**Number of hospitals**	**%**
LTV centres	20	28.6	37	52.9
Other hospitals	50	71.4	33	47.1
Total	**70**		**70**	

Organisational data

Table 1.9 Type of hospitals/services in which care was provided to people receiving invasive ventilation

	Acute hospitals				Community services			
	<18 years of age		≥18 years of age		<18 years of age		≥18 years of age	
	n	%	n	%	n	%	n	%
Yes	55	79.7	50	72.5	15	88.2	5	62.5
No	14	20.3	19	27.5	2	11.8	3	37.5
Subtotal	**69**		**69**		**17**		**8**	
Unknown	1		1		0		1	
Total	**70**		**70**		**17**		**9**	

Organisational data

Table 1.10 Type of hospitals/services in which care was provided to people receiving non-invasive ventilation

	Acute hospitals				Community services			
	<18 years of age		≥18 years of age		<18 years of age		≥18 years of age	
	n	%	n	%	n	%	n	%
Yes	59	84.3	68	97.1	15	93.8	8	88.9
No	11	15.7	2	2.9	1	6.3	1	11.1
Subtotal	**70**		**70**		**16**		**9**	
Unknown	0		0		1		0	
Total	**70**		**70**		**17**		**9**	

Organisational data

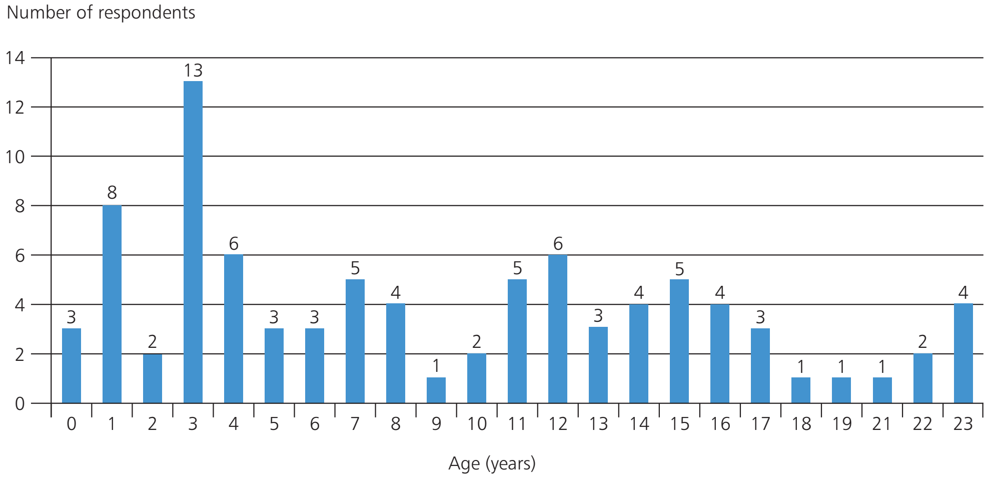


Figure 1.5 Age of children and young people the survey was completed for (n=89)

Service user/parent carer survey

Organisational data

4. Service user and parent carer online survey and focus groups

Online survey

A total of 134 service user and parent carer questionnaires were returned, of which 89 were completed well enough to be included in the analysis.

Of the 89 surveys completed 86/89 (96.6%) were completed by parent carers. The majority of all responses related to people <18 years of age (80/89; 89.9%) (Figure 1.5). Just over half of the responses related to people receiving invasive ventilation (45/89; 50.6%) and the length of time people had been receiving LTV ranged between 12 weeks and 18 years, indicating a variety of experience in LTV care.

Focus groups

Four parent carer focus groups were held, with a total of 12 participants. In addition, one young person interview was conducted. One focus group took place in Manchester, one in London and two were undertaken online. Despite the difficulties recruiting, the interviews did result in a very rich and informative dataset, which was subsequently subjected to a thematic analysis.[13]

Data from the surveys and focus groups will be presented throughout the report to supplement the clinical and organisational data.

5. Health and social care professional online survey and interviews

In total 426 health and social care professional survey questionnaires were returned, of which 243/426 (57.0%) had enough questions completed to be included in the analysis. A summary of the respondents' job roles is shown in Table 1.11. In addition, 48 clinician interviews were undertaken with respondents who had indicated a willingness to take part.

Table 1.11 Job role of the respondent as reported by health and social care professionals

	Number of respondents	%
Doctor	103	42.4
Nurse	70	28.8
Physiotherapist	32	13.2
Occupational therapist	10	4.1
Other	10	4.1
Commissioner	9	3.7
Speech and language therapist	6	2.5
Other allied health professional	3	1.2
Total	**243**	

Health and social care professional survey

A majority of respondents worked in acute hospitals where LTV was initiated (134/243; 55.1%) and 43/243 (17.7%) were based in the community (Table 1.12). Respondents mainly worked in a mixed locality (121/243; 49.8%) with only 20/243 (8.2%) based in a mainly rural location. A majority of respondents provided care for people <18 years of age (119/243; 49.0%) and 34/243 (14.0%) of respondents provided care to people both <18 years and ≥18 years of age.

Table 1.12 Type of setting in which the respondent was employed as reported by health and social care professionals

	Number of respondents	%
Acute hospital sector – LTV centre (LTV is initiated)	134	55.1
Acute hospital sector – non-LTV centre (LTV is not initiated)	59	24.3
Community sector (at home)	43	17.7
Commissioning organisation	15	6.2
Hospice or respite care	13	5.3
Community sector (residential/ nursing home (incl. specialist care)	12	4.9
Ambulance service	1	<1
Other	14	5.8
Total	**243**	

Answers may be multiple; n=243
Health and social care professional survey

Quick reference guide to denominators

Lead clinician questionnaire	**229**
Acute admission questionnaire	**152**
Community team questionnaire	**96**
Tracheostomy insertion questionnaire	**50**
Case reviewer data	**149**
Organisational questionnaire - LTV centres <18 years	**20***
Organisational questionnaire - LTV centres ≥18 years	**37***
Organisational questionnaire - community <18 years	**17**
Organisational questionnaire - community ≥18 years	**9**
Service user and parent carer survey	**89**
Health and social care professional survey	**243**

*This denominator was self-defined at a hospital level and varies throughout the report depending on the services provided within a hospital e.g. it may be an LTV centre for one aspect of care but not another.

Key Findings

1. There is no Classification of Interventions and Procedures (OPCS) code for LTV, and the way hospitals record the details of people on LTV varies
2. 3,061 people, from 113 hospitals within 94 Trusts/ Health Boards were reported to be on LTV during the study period. This was likely to be an under-representation due to coding and data returns

2

What did service users, families and care teams think?

- themes arising from the online surveys, focus groups and interviews

This chapter provides a summary of the themes which came out of the online surveys, focus groups and clinician interviews. NB: Due to the different data sources the denominator will vary. To help this, data sources have been quoted throughout the chapter.

Themes identified from the online surveys

Service user and parent carer survey

In general, the quality of the LTV service received by service users and parent carers was rated highly. Of the 89 respondents, 87 answered this question and 45/87 (51.7%) respondents rated the quality as excellent, and 81/87 (93.1%) at 5-7 on the seven point scale used (Figure 2.1).

However, 31/81 (38.3%) respondents did not feel they received the full range of health services they or their child needed (Table 2.1). Several comments were made that some healthcare professionals, not usually involved in LTV care, had limited understanding of ventilation and the related equipment.

Table 2.1 Full range of health services needed to keep well were received

	Number of respondents	%
Yes	50	61.7
No	31	38.3
Subtotal	**81**	
Not answered	8	
Total	**89**	

Service user/parent carer survey

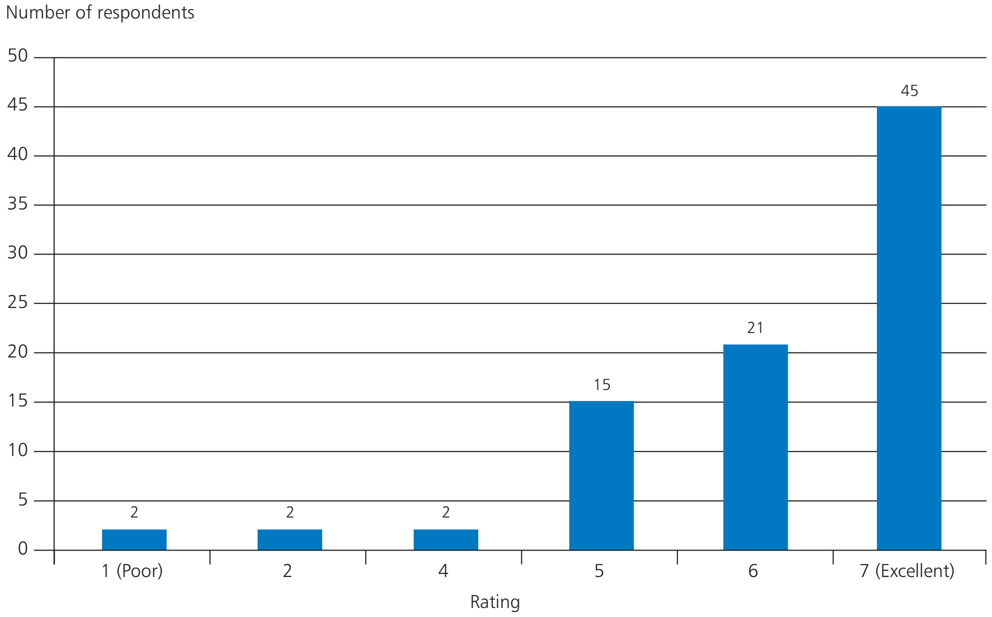


Figure 2.1 The quality of the long-term ventilation care received as rated by service users and parent carers *(n=87, not answered in two)*

> ***"Local hospital is lacking in knowledge and facilities to cope with a LTV child that is ill. GP also relies on lead children's hospital or us as parents for guidance"***
>
> ***Service user/parent carer***

> ***"Local hospital aren't trained in non-invasive bilevel ventilation so either dislike admitting her, or will admit on the proviso that we do not leave her side throughout the whole time she's using her ventilator"***
>
> ***Service user/parent carer***

Seventy respondents provided free-text comments that related to areas of LTV care that worked well, and 59 respondents provided free-text comments about things that could be improved (Table 2.2).

Table 2.2 Most common free-text comments made by respondents to the service user/parent carer survey

Aspects of LTV services that worked well	Aspects of LTV services that could be improved
27 responses referred to a positive experience of access to the specialist LTV team for support (e.g. prompt outpatient reviews, telephone access and email contact when needed)	14 responses raised issues about the competence or training of staff providing care in the community
23 responses were in relation to skilled or caring healthcare professionals	10 responses were with in relation to access to advice or follow-up arrangements
11 responses were about the convenience of home assessments for sleep studies	6 responses commented that access to sleep studies could be improved
11 responses were about access to equipment	5 responses were that local hospitals did not have the necessary knowledge of LTV to provide effective care
7 responses were with regard to training received	

Answers may be multiple; n=70 respondents commenting on where services worked well and n=59 respondents commenting on what could be improved
Service user/parent carer survey

Health and social care professional survey

In 32/234 (13.7%) of the healthcare and social care survey responses, it was considered that healthcare services for LTV worked extremely well 169/234 (72.2%) healthcare professionals rated the service at 5-7 on the seven point scale used (Figure 2.2).

Two hundred and nineteen respondents provided free-text comments that related to areas of LTV care that worked well and about clinical aspects of LTV services that could be improved (Table 2.3)

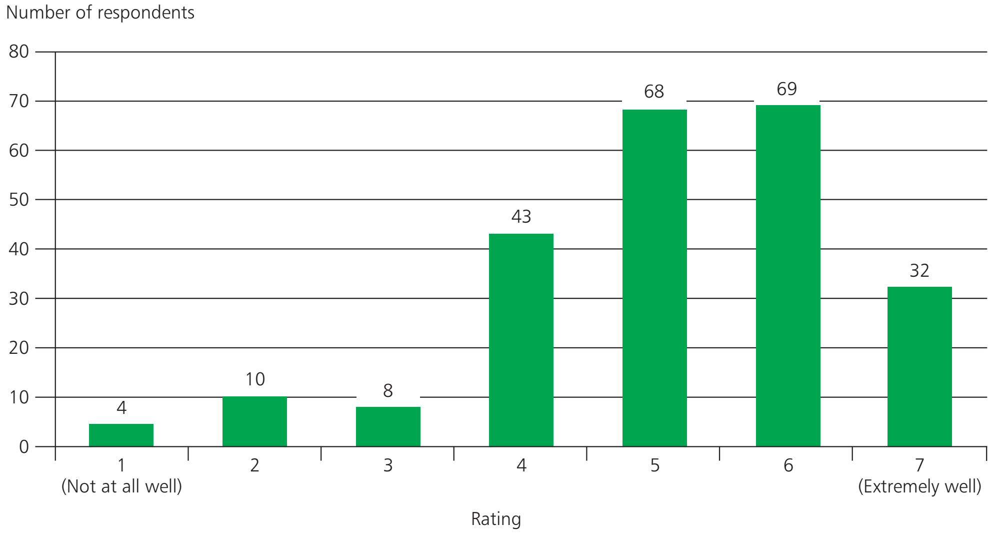


Figure 2.2 How well the healthcare services worked that were provided to people on LTV, as rated by health and social care professionals (n=234, not answered in nine)
Health and social care professional survey

Table 2.3 Most common free-text comments as reported by health and social care professionals

Aspects of LTV services that worked well	Aspects of LTV services that could be improved
138 responses referred to team working and communication between members of the MDT and others (social services, commissioners) involved in the delivery of the LTV pathway and care packages	115 responses referred to team working, communication and access to members of the wider MDT (including physiotherapy, speech and language therapy and psychology) as well as social care
35 responses related to access to services (either the availability of home assessments or systems that facilitated rapid advice and assessment for unstable people on LTV)	70 responses referred to access to services
26 responses referred to training of both service users/ parent carers and staff	48 responses referred to the need for improved knowledge and skills (including training)
30 responses referred to equipment	5 responses were that local hospitals did not have the necessary knowledge of LTV to provide effective care
	43 responses referred to the funding/commissioning of services
21 responses related to hospice/respite services	15 responses referred to better access to hospice/respite care
14 responses referred to the initiation of LTV	38 responses referred to delays in hospital discharge
12 responses referred to outreach services	31 responses referred to the staffing of LTV services

Answers may be multiple, n=219

Health and social care professional survey

The most common theme about what went well referred to team working and communication between members of the multidisciplinary team. The most common theme for improvement was the need for improved access to services: more inpatient beds, better access to outpatient reviews or services located closer to the person's home to reduce the need to travel.

The effectiveness of other services that impacted on the wellbeing of people treated with LTV, was rated at a level of 5-7 by 94/194 (48.5%) respondents (Figure 2.3). This suggested that as a group they believed there was more room for improvement in non-clinical than in clinical support for this group of people.

Commissioning arrangements for LTV services were raised as an issue which requires improvement by both people receiving LTV and by healthcare professionals who delivered LTV care. However, some of the positive comments made in response to the surveys about these services suggested that in some areas there are examples of good practice or models of care. One example was that due to specialised commissioning there was no waiting and good access to experts.

Themes identified from the qualitative focus groups and interviews

Qualitative interviews were undertaken with people on LTV and parent carers as well as professionals involved in the delivery of LTV care. Thematic analysis revealed a number of areas that people on LTV, parent carers and healthcare professionals identified as challenging and in need of improvement (Table 2.4). These overlapped considerably with the areas identified in the online surveys.

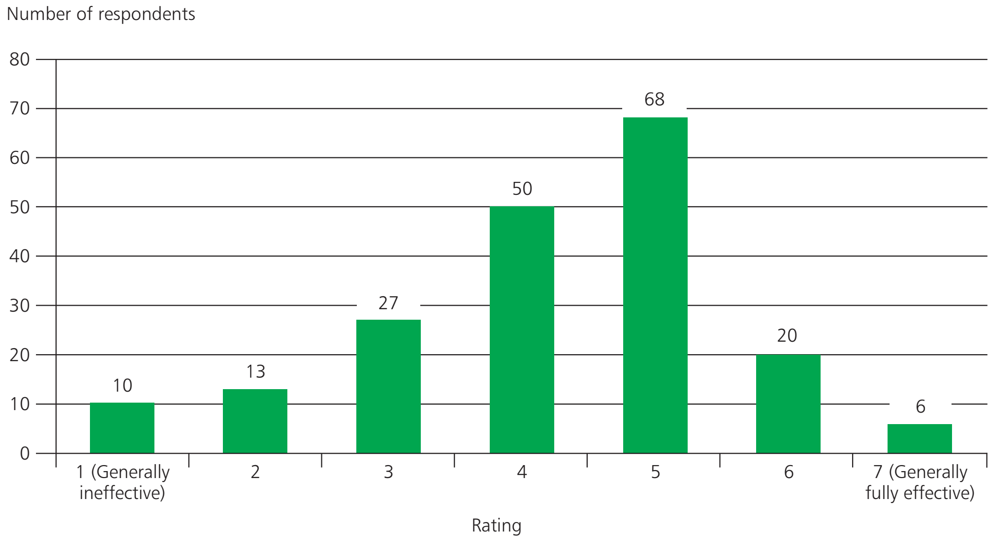


Figure 2.3 The effectiveness of other services, such as education, social care, voluntary care and independent services on health and well-being of people on LTV as rated by health and social care professionals (n=194; not answered in 49)

Health and social care professional survey

Table 2.4 Areas of improvement identified by interviews with service users/parent carers and health and social care professionals

Service user and parent carer focus groups	Health and social care professional interviews
• Complex networks/care pathways	• Complex care needs
• Communication and decision-making	• Importance of multidisciplinary approach
• Transition to adult services	• Transition to adult services
• Equipment and logistics	• Equipment
• Urgent care	• Poor community access to psychological support and therapies*
• Home care	
• Personal and family life	

**Occupational therapy, physiotherapy, speech and language therapy*

Complexity of the pathways

Parent carers described an LTV care pathway that often started at a local hospital and required transfer for specialised care. Initial uncertainty about diagnosis and treatment led to anxiety. The need for specialist care, and a perception that local hospitals did not have the ability to deal with complex ventilation, often led to a lack of trust in local units. The initial relief of receiving a diagnosis and specialist care was sometimes followed by frustration over the amount of time spent in hospital and delay in discharge. Parent carers stated there was a lack of support to discharge their child as soon as possible, which was what they wanted to do.

The main step in care pathways, as experienced by parent carers, seemed to be moving between home and hospitals rather than moving between hospital units.

> ***"I fought from the moment they told me it was going to take another 18 months to get out of hospital to even get her into a home environment (…). In terms of support, there isn't any. There isn't ANY"***
>
> ***Service user/parent carer***

> ***"We had one child that was a delayed discharge due to housing for eight months. Part of this was due to the family wanting to be in a specific area. The child had to remain on ICU for 18 months longer than they medically needed to. The impact on this is huge including inevitable developmental delay and relationships with family members"***
>
> ***Specialist Nurse***

Communication and decision-making

In such a complex area of clinical practice, effective communication is a key element of providing LTV care. Parent carers described communication that included mixed or inconsistent messages and technical jargon, which made it difficult to know if they were making the right choices.

> ***"At that point, that's when it was decision time to do a tracheostomy or not. That was a painful a decision, when he went for a tracheostomy, because there was lots of different opinions"***
>
> ***Service user/parent carer***

Parent carers often sought information themselves and described how engaging with peers was often a key part of the LTV learning process. Sharing of information would mostly happen in the hospital setting, as that was one of the few places LTV parent carers had the time and opportunity to engage with each other.

Parent carers valued communication that was co-ordinated between clinicians and between hospitals. Good hospital experiences were as a result of a holistic and co-ordinated approach, where parent carers felt they had access to the right people and the right information.

> ***"They were all at that meeting, they all came to that meeting, and I asked them honestly what their opinion was, and they were very honest but very kind"***
>
> ***Service user/parent carer***

Arrangements for the transition to adult services

Transition to adult services was also identified by parent carers and healthcare professionals as an area for improvement. Some parent carers felt that little or no information or support was provided. Furthermore they reported that the professionals involved sometimes had a poor understanding of what the change meant in practice. For example, paediatric clinicians did not know what to expect of adult services, and adult clinicians did not know what LTV support the children had previously received.

Clinicians also noted that the arrangements for transition to adult services were not consistent. The pathway was often disjointed and the level of available support reduced as soon as transition of care took place. The increasing number of young people on LTV surviving into adulthood was also highlighted, emphasising the importance of improved transition arrangements.

> ***"Transition is awful. Start very, very early, try and get all your questions sorted, and fight for everything"***
>
> ***Service user/parent carer***

> ***"The people who are meant to know the most about your healthcare, can't even have an answer. Sometimes I think it's daunting enough currently, but it's even worse when no one knows what's going to happen in the future: nobody has an answer. Sometimes I think it's scary enough as it is, moving across, makes it worse when nobody has a clue what's going to happen when it actually comes to it"***
>
> ***Service user/parent carer***

> ***"There is a tsunami of children about to transition. The warnings are clear but we have no plans in place to deal with it"***
>
> ***Consultant in Critical Care***

> ***"Children are surviving into adulthood with more complex healthcare needs and many require invasive ventilation. We know this, and so do our adult colleagues but we have yet to sit down and come up with a plan. Joint transitional clinics should be a normal planned part of the pathway, not something reactive 2 months before the 18th birthday"***
>
> ***Paediatric Respiratory Consultant***

Equipment

From a service user and parent carer perspective, LTV equipment and its maintenance was reported as a major source of concern. No concerns were expressed about equipment during hospital stays, whereas some parent carers expressed anxiety about what could happen if equipment went wrong at home.

> ***"Ordering of consumables is a real challenge. It should absolutely be the responsibility of the community/district nurse teams in the child's locality but this is often not done. When the missing items include suction catheters for example this can be really dangerous"***
>
> ***Consultant Nurse***

Healthcare professionals also described great variation in the arrangements for purchasing equipment. Arrangements varied between clinical commissioning groups was noted during the clinician interviews, such that individual hospitals could have differing arrangements for purchasing depending on the person's address. Some services used a block contract and others required individual service user requests. Inconsistent or unclear funding arrangements were reported as being unhelpful when dealing with the consumables required on a day-to-day basis. This highlighted the importance of effective arrangements for the provision of equipment.

> ***"There is such inconsistency regarding funding agreements. We cover multiple CCGs and each has their own opinion. This affects access to equipment and time for procurement depending where you live. Why can't we have a standardised approach across England? This is the only way we can ensure consistency"***
>
> ***Paediatric Respiratory Clinical Nurse Specialist***

> ***"If it doesn't work, I guess we've got a spare one for him to go out.... but if it breaks, like it has done, I've only got one left, and if that doesn't work, then he can't breathe, and he'd die"***
>
> ***Service user/parent carer***

Urgent care

Parent carer experiences of readmission to hospital, associated with medical deterioration, varied considerably. In some hospitals, they were not allowed on the ward, while in others they were required to provide LTV care, either by themselves or by supplying carers.

> ***"It's my responsibility to ensure that I have all the emergency equipment, even though we're in their building, their hospital, and the nurse has clinical responsibility for my child"***
>
> ***Service user/parent carer***

Acute admission was sometimes perceived positively illustrating the issues associated with LTV care at home.

> ***"The only time I can really relax is when he is admitted to the intensive care unit"***
>
> ***Service user/parent carer***

Many parent carers saw transfer out of hospital as the main milestone on the LTV journey. Many had experienced delays in transfer out of hospital, some lasting for months. Families felt these delays were often linked to a lack of communication between hospitals and community services, leading at best to uncertainty and at worst, to gaps in LTV care.

> ***"It's just a juggle, your whole life is a juggle. Once you're back from hospital, that's when the juggle starts"***
>
> ***Service user/parent carer***

Access to the multidisciplinary team and other therapies

Healthcare professionals identified that in the majority of hospitals, access to the full range of non-medical professional groups, required to provide care for this complex group of people on LTV, needed to be improved. This included poor access to physiotherapy, occupational therapy, speech and language therapy, dietetics and psychology.

> ***"Having access to specialist physiotherapists is so important for children on long term ventilation. Without them we would have more admissions and children themselves would have worse outcomes"***
>
> ***Paediatric Consultant***

The chapters that follow will provide a more in depth review of the areas highlighted here.

Key Findings

3. Health and social care survey data highlighted a number of improvements that could be made to LTV services, as well as areas of good care, which were often similar – Table 2.3 including:

- Access to the wider multidisciplinary team - worked well 138/219 (63.0%) and could be improved 115/219 (52.5%)
- Access to services - worked well 35/219 (16.0%) and could be improved 70/219 (32.0%)
- Improved clinical knowledge and skills about LTV - worked well 26/219 (11.9%) and could be improved 48/219 (21.9%)
- Respite/hospice care - worked well 21/219 (9.6%) and could be improved 15/219 (6.8%)

4. Health and social care survey data highlighted a number of additional improvements that could be made to LTV services – Table 2.3

- Funding/commissioning arrangements (43/219; 19.6%)
- Delays in hospital discharge (38/219; 17.4%)
- Staffing of LTV services (31/219; 14.2%)

5. Parent carers reported that the initial relief of receiving a diagnosis and specialist care was sometimes followed by frustration over the amount of time spent in hospital and delayed discharge
6. Transition to adult services was also identified by parent carers and healthcare professionals as an area for improvement. Parent carers felt that little or no information or support was provided. Furthermore they reported that the professionals involved sometimes had a poor understanding of what the change meant in practice
7. Clinicians also noted that the arrangements for transition to adult services were not consistent. The pathway was often disjointed and the level of available support reduced as soon as transition of care took place
8. Clinician interviews highlighted variations between clinical commissioning groups such that individual hospitals could have differing arrangements for purchasing depending on the person's address
9. Inconsistent or unclear funding arrangements were reported in the health and social care professional survey, as being unhelpful when dealing with the consumables required on a day-to-day basis

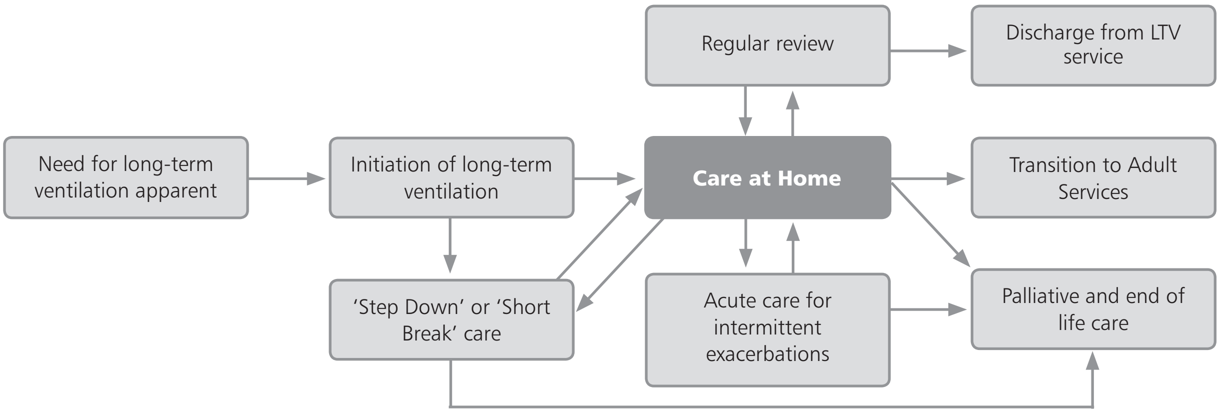
3

LTV care pathway and services: home to hospital and back

This chapter presents data on service planning and commissioning and what the care teams look like at home and in hospitals. Discharge from hospital and the transition to adult services is also described. NB: Due to the different data sources the denominator will vary. To help this, data sources have been quoted throughout the chapter.

A decision to initiate and provide long-term ventilation (LTV) for any person is rarely a straightforward one. LTV may be initiated for some following a period of acute or critical illness or difficulty/failure in weaning from respiratory support. For others, there may be a more gradual decline in overall respiratory function and LTV is initiated in a more planned context. Regardless of the reason, the pathway from specialist to non-specialist and then to community and home-based care can be slow to navigate. Furthermore, it may be difficult to define with certainty at the beginning whether LTV will be used as bridge to respiratory recovery or as a lifelong 'destination' therapy.

Recommended care pathways differ to some extent in different parts of the UK and for the age groups involved.[14-17] An example care pathway for LTV and the core standards that underpin the pathway is shown in Figure 3.1.



Throughout this pathway, each child and young person needing long-term ventilation, and their families, should have the information, support and care that they need, in particular:

- A lead consultant from the Tertiary Long-Term Ventilation Service
- A nominated Community Children's Nurse who will liaise with local services as required and may also be the 'key worker'
- An agreed 'Personal Care Plan'
- A review of their care at least annually

Children needing Level 2 or 3 care, and some needing Level 1 ventilatory care who have other medical conditions, should also have:

- A nominated 'key worker'
- 24/7 access to children's nursing support who will be able to access medical advice if required

Figure 3.1 Examples of an LTV pathway and the core standards that underpin it. Reproduced from the Quality Review Service (formally West Midlands Quality Review Service).[16]

Table 3.1 Annual audit of people on LTV undertaken in LTV centres

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Yes	10	45.5	22	53.7
No	12	54.5	19	46.3
Subtotal	**22**		**41**	
Unknown	2		2	
Total	**24**		**43**	

Organisational data

Local data collection for people on LTV

Table 3.1 shows that an annual audit of people on LTV was undertaken in 32/63 (50.8%) sites where LTV was initiated or outpatient care was provided. All 22 centres in which <18 year olds were cared for collected specific data on people who had a tracheostomy and who were ventilated. This may have been due to better coding of tracheostomy insertions.

The number of people <18 years of age reported to be on invasive LTV varied from 1-50 per centre and for non-invasive ventilation, 7-314 per centre. In 4/22 (18.2%) LTV centres, data collection was ongoing at the time of this study to determine whether LTV improved survival. Organisational data from adult LTV centres is not presented here as it included people over the age of 25.

Routine data collection about people on LTV was undertaken in 8/15 (53.3%) community organisations. Between 1-15 people per organisation were reported to be receiving invasive ventilation and between 2-39 people non-invasive ventilation at the time of data collection. Data indicated that only 2/15 (13.3%) community organisations performed an annual audit. Whilst nine community organisations returned an organisational questionnaire, only one reported that a record was kept of the number of people ≥18 years of age receiving LTV. Data collection from community organisations was limited by the ability to identify them to request data.

Service planning and commissioning

The online survey showed that 68/167 (40.7%) health and social care professionals rated the commissioning of LTV services, over the previous five years, as 5-7 on the seven point scale used (Figure 3.2).

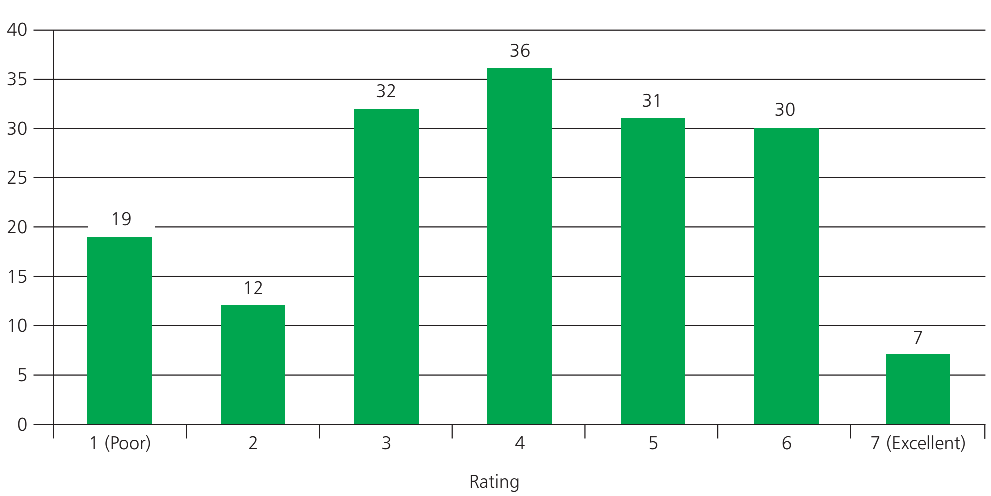


Figure 3.2 Overall commissioning arrangements for LTV services in the last 5 years as rated by health and social care professionals (n=167, not answered in 76)
Health and social care professional survey

The most common free-text comments mentioned overlap or disagreement about who commissioned what service. Also delays in, or lack of, formal commissioning arrangements. Comments on what might help, included the appointment of key professionals, such as a nurse co-ordinator, to facilitate communication between specialist and non-specialist hospital teams, the service user, their community teams and parent carers (see Appendix 2). In the interviews, clinicians also mentioned commissioning as an area of improvement.

> ***"The postcode lottery definitely exists when it comes to commissioning of care packages for children on ventilation. We end up having prolonged hospital stays due to delays in decisions regarding packages of care"***
>
> ***Paediatric Respiratory Consultant***

> ***"I don't understand why commissioners don't hand over to each other. We as clinicians need to but when a child transitions they need a whole new commissioning team and review which takes a great deal of time. I also don't understand why the commissioners for complex ventilation can't be the same people for children and adults in the locality. It would make things much more fluid"***
>
> ***Consultant in Critical Care***

> ***"We work across 7 CCGS and all have different commissioning pathways. It's so time consuming and inefficient and inevitably leads to delays"***
>
> ***Continuing Care Nurse***

> ***"We have recently changed our pathways of commissioning after meeting with all key stakeholders including care providers. We are 6 months into this new pathway and I can't tell you how better things are for the children, families, staff and care teams. We needed a co-ordinated approach for these children and families"***
>
> ***Paediatric Respiratory Clinical Nurse Specialist***

Data from the LTV community team clinical questionnaire showed that for the majority of people (73/85; 85.9%), healthcare was the primary source of funding. There were 36/85 (42.4%) people who received social care funding, and only 15/85 (17.6%) people had a personal healthcare budget in place (Table 3.2).

Table 3.2 Responsibility for funding of services

	Number of people	**%**
Healthcare funded	73	85.9
Social care funded	36	42.4
Personal healthcare budget	15	17.6
Other	3	3.5
Charitable funding	2	2.4
Private funding	1	1.2
Insurance	0	0.0
Subtotal	**85**	
Unknown	11	
Total	**96**	

Answers may be multiple; n=85
Community team clinical questionnaire

Organisational data showed that service planning/commissioning for LTV was formalised in 13/19 (68.4%) LTV centres in which care was provided to people <18 years of age, and 25/37 (67.6%) for people aged ≥18 years. There was considerable variation in what was commissioned, with very little respite care (9/54; 16.7%) (Table 3.3).

Similar data, taken from the case reviews, highlighted that whilst the majority of those aged <18 years would meet the criteria for hospice referral due to their physical frailty, the arrangements would differ for adults. Young adults, with conditions which had led to LTV, were often ineligible for short break/respite care as their life expectancy was not as easy to define. In addition, much of the hospice care provided in the UK is provided by third sector organisations. This care may not be recognised within service planning and is only partially funded by the NHS.[18]

The absence of respite care was re-enforced by data from the health and social care professional survey, which provided some details on where short break/respite care was provided. There was a marked difference between the under and over 18 age groups (Figure 3.3).

Table 3.3 Services that were commissioned in LTV centres

	<18 years of age		≥18 years of age	
	Number of hospitals	**%**	**Number of hospitals**	**%**
Tertiary children's LTV service	14	100.0	20	50.0
Short break/respite service	7	50.0	2	5.0
Home support service	6	42.9	9	22.5
Step down service	1	7.1	5	12.5
Subtotal	**14**		**40**	
Unknown	7		0	
Total	**21**		**40**	

Answers may be multiple
Organisational data

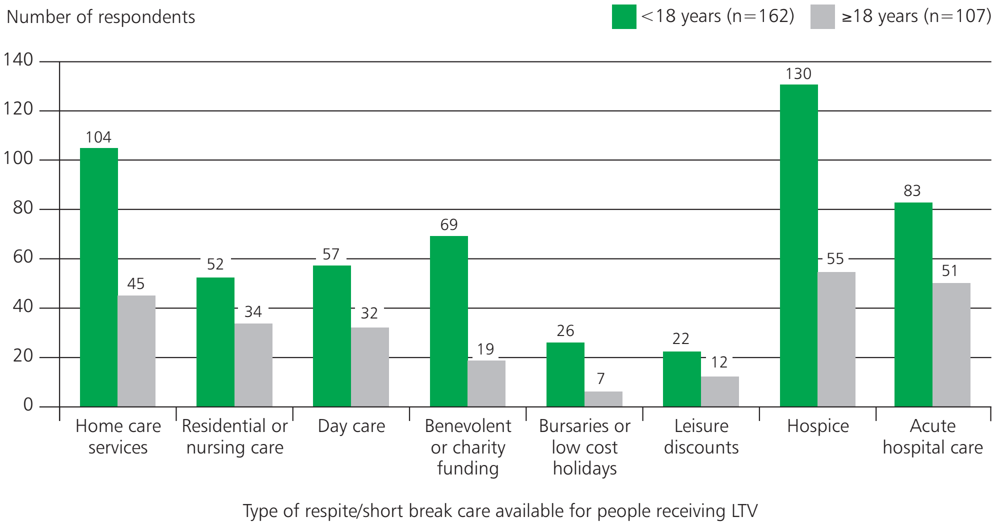


Figure 3.3 Short break/respite care available as reported by health and social care professionals (answers may be multiple; n=162 for <18 years, not answered in 81 and n=107 for ≥18 years, not answered in 136)
Health and social care professional survey

What care teams looked like

Guidance and standards for children and young people receiving LTV state that they should have access to a multidisciplinary team to assist with their needs in all locations of care.[15-17] According to the lead clinicians who completed a questionnaire, parent carers and other family members were the most common care givers at home prior to an admission, with only 28/213 (13.1%) people having help from registered healthcare staff, from either the NHS or other providers across both age groups (Table 3.4).

Specialist help available to people on LTV in the community was reported by lead clinicians, and is shown in Table 3.5.

Table 3.4 Care provision in the community and age

	<18 years of age		≥18 years of age	
	Number of people	%	Number of people	%
Family/parent carers	102	80.3	65	75.6
Registered healthcare staff (NHS)	37	29.1	10	11.6
Carers (other provider)	33	26.0	21	24.4
Carers (NHS)	30	23.6	12	14.0
Registered healthcare staff (other provider)	22	17.3	6	7.0
No care provision	9	7.1	3	3.5
Self-care	3	2.4	17	19.8
Other	6	4.7	6	7.0
Subtotal	**127**		**86**	
Unknown	5		1	
Total	**132**		**87**	

Lead clinician questionnaire

Table 3.5 Access to specialist help in the community by type of ventilation received prior to admission (data relates only to people in the study who were admitted to hospital)

	Invasive		Non-invasive		Subtotal	Unknown	Total
	Number of people	%	Number of people	%	Number of people	Number of people	Number of people
Tracheostomy specialist	19	47.5	6	7.3	25	3	**28**
Physiotherapist	34	85.0	49	59.8	83	5	**88**
Occupational therapist	26	65.0	30	36.6	56	3	**59**
Speech and language therapist	29	72.5	41	50.0	70	5	**75**
Nutritional support/ dietetics	33	82.5	54	65.9	87	6	**93**
None	2	5.0	7	8.5	9	1	**10**
Other	7	17.5	21	25.6	28	2	**30**
Subtotal	**40**		**82**		**122**	**9**	**131**
Unknown	7		19		26	0	**26**
Total	**47**		**101**		**148**	**9**	**157**

Answers may be multiple
Lead clinician questionnaire

Not all people had access to a physiotherapist, occupational therapist or dietitian. However, these specialists were accessed more frequently than speech and language therapists or access to a tracheostomy nurse specialist, for those receiving invasive ventilation.

Whilst most LTV centres had a medical lead for the LTV service, the organisational data showed that fewer had non-medical leads (Table 3.6). The composition of the LTV teams in LTV centres varied. Whilst most had respiratory physiotherapy, some relied on the general physiotherapy rota to provide cover when people were admitted acutely (Table 3.7). A minority of LTV services had speech and language therapy as part of their team and even fewer had psychology (Table 3.8).

Table 3.6 Identified leads for people receiving LTV

	Identified medical lead clinician				Identified non-medical lead			
	<18 years of age		≥18 years of age		<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%
Yes	18	90.0	36	94.7	16	80	22	61.1
No	2	10.0	2	5.3	4	20	14	38.9
Subtotal	**20**		**38**		**20**		**36**	
Unknown	0		1		0		3	
Total	**20**		**39**		**20**		**39**	

Organisational data

Table 3.7 Provision of physiotherapy for acute LTV care

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Respiratory physiotherapy service	15	78.9	30	78.9
Dedicated LTV physiotherapist	8	42.1	20	52.6
Other physiotherapy	4	21.1	2	5.3
General physiotherapy rota	3	15.8	13	34.2
Physiotherapy not provided	0	0.0	1	2.6
Subtotal	**19**		**38**	
Unknown	1		1	
Total	**20**		**39**	

Answers may be multiple
Organisational data

Table 3.8 Specialties within the LTV service

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Medical: consultant	19	95.0	38	97.4
Medical: non-consultant	9	45.0	18	46.2
Nursing: specialist nurse (Agenda for Change band 7 or above)	19	95.0	29	74.4
Nursing: (Agenda for Change band 5 and 6)	8	40.0	17	43.6
Physiotherapist	16	80.0	26	66.7
Occupational therapist	12	60.0	13	33.3
Psychologist/psychological support	7	35.0	7	17.9
Speech and language therapist	7	35.0	14	35.9
Dietician	7	35.0	14	35.9
Other	6	30.0	18	46.2
Total	**20**		**39**	

Answers may be multiple
Organisational data

Admission pathway for acute exacerbations

Many children <18 years of age, experiencing an acute increase in the severity of their condition, were admitted to a specialist paediatric tertiary centre (SPTC), and were more commonly receiving invasive ventilation (Table 3.9).

In general, SPTCs may be further from home for the service user and family, making the pathway of care more complex. It should be noted that this study deliberately included more people receiving invasive ventilation. Detailed information about admissions is also presented in Chapter 5.

Table 3.9 Size of unit and type of ventilation for people admitted

	Invasive (tracheostomy)		**Non-invasive (mask)**	
	Number of people	**%**	**Number of people**	**%**
District general hospital <500 beds	3	6.1	22	24.2
District general hospital ≥500 beds	9	18.4	21	23.1
University teaching hospital	15	30.6	27	29.7
Specialist paediatric tertiary centre	22	44.9	21	23.1
Subtotal	**49**		**91**	
Unknown	0		1	
Total	**49**		**92**	

Admitting clinician questionnaire n=141, unknown in 11

Whilst most people were cared for, at least initially, in a hospital within 25 miles from their home, admitting clinicians reported that 31/148 (20.9%) people travelled further, and of these, six travelled 51-100 miles (Table 3.10).

Table 3.10 Distance of the hospital from the person's normal residence

	Number of people	%
<25 miles	117	79.1
>100 miles	1	0.7
25-50 miles	24	16.2
51-100 miles	6	4.1
Subtotal	**148**	
Unknown	4	
Total	**152**	

Admitting clinician questionnaire

More children and young people travelled further for their admission to an LTV centre (Table 3.11). These data may reflect the greater complexity of younger people, more of whom were receiving invasive ventilation and/or simply that there were fewer, more wide-spread, critical care facilities for children and young people.

Where it was documented in the case notes, case reviewers reported that most people were transported to hospital in the family car or by ambulance (50/125; 40.0%). They commented that there may be challenges for emergency services in providing adequate space, equipment and the relevant staff training/competences to enable them to confidently transfer all people on LTV.

CASE STUDY 1

Difficulty in organising an admission

A baby with a rare heart condition had a planned admission to a large university teaching hospital to change a feeding tube. The baby required ventilation at night via a tracheostomy tube and the only location deemed safe for this care was the paediatric critical care unit. This required an overnight stay during which time the baby's parent carers delivered most of the care.

Case reviewers commented that whilst location of care was safe, it was often extremely difficult to organise such admissions due to pressure on paediatric critical care beds.

Table 3.11 Distance to lead LTV centre by age of the service user

	<18 years of age		≥18 years of age	
	Number of people	**%**	**Number of people**	**%**
<25 miles	56	53.8	26	65.0
25-50 miles	32	30.8	11	27.5
51-100 miles	13	12.5	3	7.5
>100 miles	3	2.9	0	0.0
Subtotal	**104**		**40**	
Unknown	3		3	
Total	**107**		**43**	

Admitting clinician questionnaire n = 150, unknown in two

Discharge pathways

Early planning for discharge home during a hospital admission, for any reason, helps avoid a delay. Best practice on preparing for discharge for people receiving LTV is available.[14,17]

Discharge after tracheostomy and initiation of LTV

Clinicians who led the admissions when there had been a new tracheostomy insertion for LTV (n=50) stated that there had been delay at discharge due to non-clinical issues for 19/46 (41.3%) people, but unknown in four (Table 3.12). This related to issues such as re-housing, care packages and training.

Table 3.12 Non-clinical problems which contributed to a delay in discharge for people admitted for a tracheostomy insertion

	Number of people	%
Yes	19	41.3
No	27	58.7
Subtotal	**46**	
Unknown	2	
Not applicable	2	
Total	**50**	

Tracheostomy insertion questionnaire

In 42/50 (84.0%) people with a new tracheostomy a care package was available. In 40/42 (95.2%) of these people the care package in place clearly stated all of their needs, in the view of clinicians completing the tracheostomy insertion questionnaire. In 29/40 (72.5%) a 'tracheostomy passport' was included. The provision of a 'tracheostomy passport' was a key recommendation of the 2014 NCEPOD report on adult tracheostomy care and is now embedded in national standards for all ages of service user.[19-21] The 'passport' should include essential information about the tracheostomy size and type, aiding rapid communication, particularly in an emergency.

The GP was informed of the tracheostomy insertion in just 19/25 (76.0%) people. GPs may well find themselves with a key role in clinical management particularly at the point of, or after transition to adult services. Therefore, not being involved is a missed opportunity and consideration should be given on how to involve them at an earlier stage. GP reviewers in this study suggested that e-communication may be the most efficient method of communication (see Appendix 2).

CASE STUDY 2

Re-admission to a hospital that is different to the one providing LTV care

> A premature baby was discharged home from a large neonatal intensive care unit receiving non-invasive ventilation at night via a mask. The baby required re-admission within two days to a local district general hospital. Here the baby was unknown to the staff and the team was unfamiliar with the ventilator used. They were also uncertain how to deal with the baby's respiratory deterioration that resulted in intubation in the middle of the night by a consultant anaesthetist and subsequent transfer to a regional paediatric critical care unit.
>
> *Case reviewers commented on the fragility of the person's care pathway, as well as the difficulty that local district general hospital teams face in dealing with such emergency admissions, particularly out of hours.*

Discharge pathway after an acute admission

Case reviewers reported evidence of discharge planning in 64/126 (50.8%) sets of notes (Table 3.13). Whilst some admissions were relatively short there were examples where care teams had not been adequately prepared for discharge, and re-admission occurred quickly or delay ensued.

Table 3.13 Evidence in the notes that discharge planning started prior to discharge

	Number of people	%
Yes	64	50.8
No	62	49.2
Subtotal	**126**	
Unable to answer	23	
Total	**149**	

Case reviewer data

Evidence that the person's usual community team was involved in discharge planning was missing in 73/103 (70.9%) sets of notes. Furthermore, evidence that their usual lead LTV centre team was involved was missing in 68/113 (60.2%) sets of notes. However, it was a positive finding that the person's family was frequently involved (81/117; 69.2%) (Table 3.14).

At discharge from the usual LTV centre, the admitting clinician reported changes in the long-term respiratory care for 24/83 (28.9%) people, and decisions made about long-term treatment goals for 13/78 (16.7%) people (Table 3.15). The most common changes to be made to long-term respiratory care were changes to ventilation (16/24; 66.7%), the escalation plan (8/24; 33.3%) and or suction/airway clearance (7/24; 29.2%) (See Chapter 6).

Table 3.14 Evidence in the case notes of who was involved in discharge planning

	Usual community team		Usual LTV centre team		Family	
	Number of people	%	Number of people	%	Number of people	%
Yes	30	29.1	45	39.8	81	69.2
No	73	70.9	68	60.2	36	30.8
Subtotal	**103**		**113**		**117**	
Unable to answer	14		13		13	
Not applicable	32		23		19	
Total	**149**		**149**		**149**	

Case reviewer data

Table 3.15 Changes to respiratory care during the admission

	Significant changes made to LTV care		Significant changes to overall care		Decisions made about long-term treatment goals	
	Number of people	%	Number of people	%	Number of people	%
Yes	24	28.9	22	25.9	13	16.7
No	59	71.1	63	74.1	65	83.3
Subtotal	**83**		**85**		**78**	
Unknown	5		3		10	
Total	**88**		**88**		**88**	

Admitting clinician questionnaire

Table 3.16 A revised care plan was provided at discharge from hospital

	Number of people	%
Yes	43	34.7
No	81	65.3
Subtotal	**124**	
Unknown	15	
NA – transferred	13	
Total	**152**	

Admitting clinician questionnaire

The admitting clinicians reported that a discharge summary was provided for 138/146 (94.5%) people (but unknown for five people) and a revised care plan was provided at discharge for 43/124 (34.7%) people (this was unknown or not applicable for a further 28) (Table 3.16).

Case reviewers and SAG members also commented about the need to ensure that communication between NHS and non-NHS providers occurs. For example, hospices form a vital part of the service user pathway for many. This was also shown in the data from the health and social care professional interviews.

CASE STUDY 3

Excellent multidisciplinary communication

A young teenager receiving nocturnal bilevel ventilation repeatedly failed to wean to non-invasive ventilation after a planned surgical procedure. A joint multidisciplinary team/service user/parental decision was made to perform tracheostomy and they were subsequently prepared for home discharge.

Case reviewers commented on the excellent level of early communication with outside agencies including community, hospice and therapy teams during the admission.

Transition from child to adult services

Transition is defined as a process by which a young person's care moves from child to adult services. Ideally, services should be sufficiently flexible to meet the individual needs of young people up to age 25 years, accepting that those with complex long-term health issues may require an extended transition period.[22-24]

> ***"There is poor understanding of the role of hospices and the management of LTV children. Part of the problem is potentially the variance in roles across the country. There is lots of work to be done with the third sector and hospices in particular as they play such a vital role in caring for LTV children"***
>
> ***Specialist Nurse***

NICE transition guidance (NG43)[25] and other recommended programmes[26,27] include the need for planning for transition of care from child to adult services to have commenced by at least the young person's 14th birthday. Recent NCEPOD reports have shown that transition is often delayed, or has not formally occurred by 18 years, in people with complex needs.[1,28]

From the health and social care professionals' responses to the question on transition of care, 8/141 (5.7%) rated the services for transition to adult services as excellent, and 73/141 (51.8%) rated them at 5-7, on the seven point scale used (Figure 3.4).

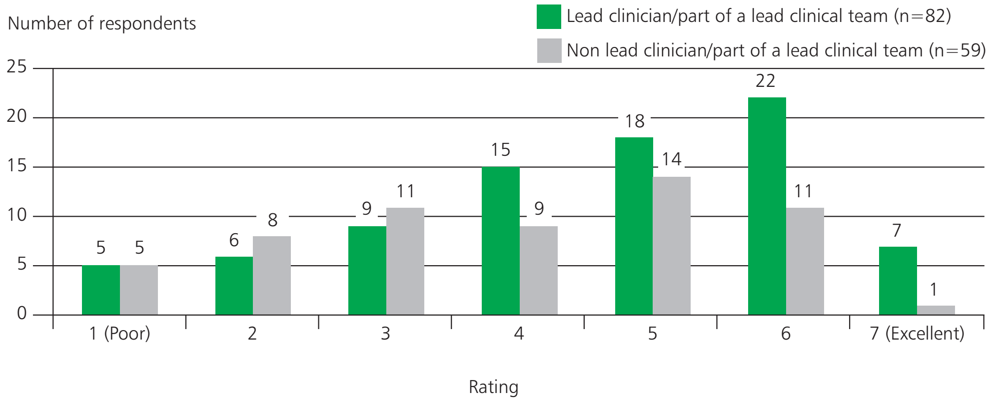


Figure 3.4 Transition arrangements from child to adult services for people receiving LTV as rated by health and social care professionals (where both data were available) (n=141, not answered in 102)

Health and social care professional survey

Table 3.17 All people had a personal care plan which included ongoing input from a multidisciplinary team as reported by health and social care professionals

	<18 years of age		≥18 years of age	
	Number of people	%	Number of people	%
Yes	102	81.0	43	55.8
No	24	19.0	34	44.2
Subtotal	**126**		**77**	
Unknown	79		101	
Not answered	38		65	
Total	**243**		**243**	

Health and social care professional survey

Personal healthcare plans in people receiving LTV were also less likely to be available for people after transition to adult services, with 102/126 (81.0%) health and social care professionals stating that they were routinely available for all people <18 years of age but only 43/77 (55.8%) for ≥18 years of age (Table 3.17).

Views from the clinician interviews about transition to adult services were abundant. There were some services that had learnt from experience and developed the role of a dedicated professional to manage a fluid transitional pathway to adult services (see Appendix 2). The role of the GP and primary care was fundamental in this but was reported as often not included.

> ***"Transition was shocking in our service so we recently appointed a Paediatric LTV Nurse who leads on this. So many children were lost in transition we needed to ensure that we had a solid pathway for children, parents and clinicians. There is a lot to learn from the severe asthma models"***
>
> ***Nurse Consultant***

> ***"It is so important to re-engage GPs with children that are ready for transition. For 18 years they are generally not the first point of contact for families but they are in adult primary care. We need to have a pathway specific to the locality the patient is in to ensure collaborative working once transition has occurred. Not only will that reduce the likelihood of communication breakdown but will support the LTV teams and GPs. In our experience the GPs are rarely involved and prepared for transition"***
>
> ***Consultant Respiratory Physician***

There were 109/229 (47.6%) people who were 14 years or older and established on LTV, for whom a lead clinician questionnaire was received. Of these:

- Transition to adult services was planned or had occurred in 76/97 (78.4%) people (12 unknown)
- A lead clinician for LTV care had been identified in adult health for 71/74 (95.9%) people (35 unknown)
- A multidisciplinary team meeting where a transition of care plan was agreed occurred for 28/91 (30.8%) people (18 unknown)
- Review in a joint paediatric transition of care clinic was undertaken for 35/96 (36.5%) people (13 unknown) and where there had not been a review it was because there was no transition clinic available for 32/61 (52.5%) people

When community clinicians were asked how LTV care could be improved, transition to adult services was raised in 5/32 (15.6%) comments. They stated that there was a need for clearer pathways to be in place (see Appendix 2).

There were examples in the case reviews of where there was an urgent need for transition to adult services to be better planned, and managed in a proactive fashion.

Organisational data on transition to adult services, from 20 LTV centres for people <18 years of age and 39 hospitals for those ≥18 years of age, is presented in Table 3.18. Whilst many organisations had a named lead clinician for transition of care, they were less likely to have a single practitioner (named worker) to co-ordinate transition of care, or an executive (board) lead who took responsibility for transition.

There were 13/19 (68.4%) LTV centres in which <18 year olds were cared for, where a process was in place to provide a written plan describing the arrangements following transition to adult services (this was not answered for one centre). In comparison 14/28 (50.0%) LTV centres for ≥18 year olds, where it was answered, did the same. It was reported from very few LTV centres that the person's GP was involved in transition of care planning (<18 years of age 7/18; 38.9% vs ≥18 years of age 8/29; 27.6%).

CASE STUDY 4
Lost to follow-up after transition to adult services

> A young adult in further education was admitted to a university teaching hospital with a two-day history of fever, increasing shortness of breath and an inability to wean off of bilevel ventilation, which was generally used at night. They were admitted and treated for a chest infection. However, during the assessment it was noted that they had not had a review of their LTV since starting college 10 months previously. A full assessment and a management plan to include direct access to the respiratory ward was completed.
>
> *Case reviewers commented that this young person had only been seen on one occasion by the adult respiratory service and had been lost to follow-up after transitioning to adult services and going to college.*

Overall, it was reorted from 11/29 (37.9%) LTV centres (not answered for 10), in which care was provided to people ≥18 years of age, that there was a difference in the degree of clinical support following transition to adult services. It was self-reported from almost all of these centres that aspects of transition planning could be improved (Table 3.19).

Table 3.18 Organisational data on planning for transition to adult services

	Named clinician for transition of care				Single practitioner to co-ordinate transition of care				Named executive lead for transition of care			
	<18 years of age		<18 years of age		<18 years of age		<18 years of age		<18 years of age		<18 years of age	
	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%
Yes	12	63.2	20	60.6	5	27.8	10	30.3	4	26.7	9	33.3
No	7	36.8	13	39.4	13	72.2	23	69.7	11	73.3	18	66.7
Subtotal	**19**		**33**		**18**		**33**		**15**		**27**	
Unknown	1		6		2		6		5		12	
Total	**20**		**39**		**20**		**39**		**20**		**39**	

Organisational data

Table 3.19 LTV centre improvements in transition services was needed

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Yes	17	100.0	30	93.8
No	0	0.0	2	6.2
Subtotal	**17**		**32**	
Unknown	3		7	
Total	**20**		**39**	

Organisational data

Case study 5 illustrates some of the many issues encountered by a young person whose complex care which includes their LTV required ongoing leadership as they transitioned to adult services.

CASE STUDY 5
Absence of leadership for LTV

A 17 year old wheelchair user with a cerebral palsy (GMFCS 4) receiving nocturnal home bilevel ventilation was admitted with a lower limb fracture to a local district general hospital under the care of the (adult) orthopaedic team. Over the next several days the many elements of good care were provided, particularly in relation to pain control by the acute pain service. They were discharged home uneventfully but with no obvious discharge plan other than a follow up in fracture clinic.

Case reviewers noted that the person cared for had a very low weight and that they were enterally fed with a nasogastric tube, though it was not recorded how long this had been present. At discharge there was no assessment as to how they would cope at home in a wheelchair whilst still in plaster. They were under the care of a paediatrician in the community but it was unclear as to who was supervising the non-invasive ventilation care and there was no obvious plan for transition to adult services .

Key Findings

10. An annual audit of people on LTV was undertaken in 32/63 (50.8%) LTV centres – *Table 3.1*
11. Not all people had access to a physiotherapist in the community (34/40; 85% invasive, 49/82; 59.8% non-invasive) or to an occupational therapist (26/40; 65% invasive, 30/82; 36.6% non-invasive) – *Table 3.5*
12. A medical lead for the LTV service was available in most LTV centres (<18 years of age 18/20; 90% vs ≥18 years of age 36/38; 94.7%) according to the organisational data – *Table 3.6*
13. The composition of the LTV teams in LTV centres varied; most included respiratory physiotherapy (<18 years of age 15/19; 78.9% vs ≥18 years of age 30/38; 78.9%) – *Table 3.7*
14. When people were admitted acutely some LTV services relied on the general physiotherapy rota to provide cover (<18 years of age 3/19; 15.8% vs ≥18 years of age 13/38; 34.2%) – *Table 3.7*
15. A minority of LTV services had speech and language therapy as part of their team (<18 years of age 7/20; 35.0% vs ≥18 years of age 14/39; 35.9%) and even fewer had psychology (<18 years of age 7/20; 35.0% vs ≥18 years of age 7/39; 17.9%) – *Table 3.8*
16. In 42/50 (84.0%) people with a new tracheostomy a care package was available. In 40/42 (95.2%) of these people the care package in place clearly stated all of their needs, in the view of clinicians completing the tracheostomy insertion questionnaire. In 29/40 (72.5%) a ‘tracheostomy passport’ was included

17. The GP was informed of the tracheostomy insertion in just 19/25 (76.0%) people
18. Commissioning of LTV services was rated 5-7 on a seven point scale by 68/167 (40.7%) health and social care professionals – *Figure 3.2*
19. Data from the LTV community team clinical questionnaire showed that healthcare was commonly the primary source of funding (73/85; 85.9%). There were 36/85 (42.4%) people who received social care funding, and only 15/85 (17.6%) people had a personal healthcare budget in place – *Table 3.2*
20. Organisational data showed that service planning/ commissioning for LTV was formalised in 13/19 (68.4%) LTV centres in which care was provided to people <18 years of age, and 25/37 (67.6%) for people aged ≥18 years of age. There was considerable variation in what was commissioned, with very little respite care (9/54; 16.7%) – *Table 3.3*
21. Where there were problems in commissioning highlighted by health and social care professionals, the most common comments mentioned overlap or disagreement about who commissioned what, delays in, or lack of formal commissioning arrangements
22. The absence of respite care was re-enforced by data from the health and social care professional survey. There was a marked difference between the two age groups – *Figure 3.3*
23. Clinicians who led the admissions when there had been a new tracheostomy insertion for LTV stated that there had been delay at discharge due to non-clinical issues for 19/46 (41.3%) people, but unknown in four – *Table 3.12*
24. Case reviewers reported evidence of discharge planning in 64/126 (50.8%) sets of notes – *Table 3.13*
25. Evidence that the person's normal community team was involved in discharge planning was missing in 73/103 (70.9%) sets of notes and evidence that their usual lead LTV centre team was involved was missing in (68/113; 60.2%) sets of notes – *Table 3.14*
26. At discharge from the usual LTV centre, the admitting clinician reported changes in the long-term respiratory care for 24/83 (28.9%) people, and decisions made about long-term treatment goals for 13/78 (16.7%) people – *Table 3.15*
27. The admitting clinicians reported that a discharge summary was provided for 138/146 (94.5%) people (but unknown for five people) and a revised care plan was provided at discharge for 43/124 (34.7%) people – *Table 3.16*
28. 11/29 (37.9%) LTV centres in which care was provided to people ≥18 years of age reported a difference in the degree of clinical support following transition to adult services. It was reported from almost all centres that transition of care planning could be improved – *Table 3.19*
29. From the health and social care professionals' responses to the question on transition of care, 8/141 (5.7%) rated the services for transition to adult services as excellent (7 on the scale), and 73/141 (51.8%) rated them at 5-7, on the seven point scale used – *Figure 3.4*
30. Transition to adult services was planned or had occurred in 76/97 (78.4%) people (12 unknown) aged over 14 years
31. 71/74 (95.9%) people at the point of transition to adult services had a lead clinician for LTV care identified in adult health (this was unknown in 35 people), but a transition care plan, agreed in a multidisciplinary team meeting, occurred for only 28/91 (30.8%) people (18 unknown)
32. Review in a joint paediatric transition of care clinic was undertaken for 35/96 (36.5%) people (13 unknown) and where there had not been a review it was because there was no transition clinic available for 32/61 (52.5%) people
33. 5/32 (15.6%) community clinicians reported a need for clearer pathways for transition to adult services to be in place
34. Very few LTV centres involved the person's GP in transition of care planning (<18 years of age 7/18; 38.9% vs ≥18 years of age 8/29; 27.6%)

4

Decision-making, communication and managing risk

This chapter presents data on decision-making with regard to the care of people on long-term ventilation (LTV), the communication with their families and between teams, and the processes involved in managing risks associated with LTV. NB: Due to the different data sources the denominator will vary. To help this the data sources have been quoted throughout the chapter.

Clear communication between healthcare professionals, people on LTV and their parent carers is of paramount importance due to the overlap between the providers of health and social care. When the decision to begin LTV is considered, the person involved, their family and care teams may have a very different understanding and set of expectations from those of the attending health professionals. Guidance on preparing people with complex long-term needs and their parent carers for making such decisions is available.[29] Once established on LTV, any changes to a person's care plan should be fully communicated.[15,16]

Decision-making

Commencing LTV

Guidance on how to conduct the decision-making process is contained in existing standards[14-17] and a recent paper on introducing an ethical framework to the provision of LTV has suggested the following good practice points on preparing families and the wider care team: [12]

- *"Standardised processes with multidisciplinary involvement are likely to improve the consistency and quality of decision-making in long-term ventilation.*
- *Novel therapies introduce uncertainty into decision-making in long-term ventilation.*
- *Parallel planning must be undertaken alongside providing long-term ventilation."*

People on LTV and parent carers were asked about their involvement in the decision-making process when LTV was commenced. Only 5/78 (6.4%) respondents, considered the process to be conducted poorly, with 13/78 (16.7%) stating that they had been included some, as opposed to all, of the time. Not all parent carers responded to this question (n=16) and in some cases recall of these events may have been difficult as some time had elapsed since the decision to commence LTV had been made.

People on LTV and parent carers were also asked whether they were aware of the impact LTV would have on their life, with 25/84 (29.8%) stating that they had not been aware of it (not answered in five). When asked about how communication might be improved 31/89 (34.8%) service users and parent carers responded that there was a need to provide more opportunities for them to ask questions (see Appendix 2). Several also indicated that they understood that giving a full picture, or predicting outcomes, would be difficult for professionals to convey. Similar information has been provided by parent carers in other published work[3] and was consistent with comments made by parent carers in the focus groups from this study.

> ***"I/We understood everything at the time but on the occasion I wasn't sure I asked questions. The whole process was relatively easy to navigate based solely on the training, information and honesty provided by my daughters LTV Team"***
>
> ***Service user/parent care***

> ***"It was done very suddenly and had no time to ask questions!"***
>
> ***Service user/parent care***

> ***"I don't think anyone would be fully aware of the life they will lead with a trachy child"***
>
> ***Service user/parent carer***

> ***"The whole process, the care package, the problems you will face , what life is like at home, how things work in the community"***
>
> ***Service user/parent carer***

> ***"In hospital the tracheostomy situation was discussed as something standard and simple and not requiring much in the way of additional equipment or care provision and the life changing impact was never mentioned. It was day to day and routine in the hospital with the suggestion that even as a single parent with a trachy vented child I would only need a minimal care package at home"***
>
> ***Service user/parent carer***

Several comments made during the clinician interviews related to the challenges of dealing with conflicting views between clinicians and parent carers. They added that this was made more complicated by social media, television and news broadcasts. Many clinicians referenced the potential benefit of forming an independent expert panel, to which people with complex needs, awaiting LTV could be referred to peer review/mediation. A multidisciplinary team of clinical experts, legal representatives, service planners and lay members was proposed to assist with difficult decision-making. Clinicians also stated that this might potentially prevent prolonged medico-legal cases and assist the person on LTV, their family and clinicians (see Appendix 2).

> ***"There are blurred boundaries of responsibilities. Having a central panel that we can take complex patients to discuss the detailed case and make a final decision will be the only way we can control this and ensure the child's best interests are always paramount"***
>
> ***Paediatric Respiratory Consultant***

> ***"Parents have unlimited access to other parents through social media and other online platforms. This can often cause competition amongst parents with regard to housing or care packages for example. It can also create unrealistic expectations and this is becoming a greater problem for our team"***
>
> ***Paediatric Respiratory Physiotherapist***

For most people already established on ventilation (168/208; 80.8%), lead clinicians reported that LTV was started as ‘destination’ therapy i.e. with no immediate plan to discontinue (Table 4.1). Case reviewers and SAG members noted that there was a relative paucity of evidence on long-term outcomes from LTV to guide future decision-making.

Table 4.1 Plan for LTV when it was commenced

	Number of people	%
As ‘destination’ therapy (with no immediate plan to discontinue)	168	80.8
As a bridge to definitive therapy or in anticipation of recovery with growth	40	19.2
Subtotal	**208**	
Unknown	21	
Total	**229**	

Lead clinician questionnaire

The decision-making process was reported as being clearly documented in the records of 52/55 (94.5%) people who had LTV initiated in the two-year study period, as identified by the lead clinician. There had been inclusion of a multidisciplinary team and parent carers in the process and in 23/55 (41.8%) people a sleep study or respiratory function tests were used in decision-making. In 4/55 (7.3%) people there had been clinical disagreement about whether LTV was the appropriate treatment modality.

NB: the method of sampling meant if LTV was initiated during the 2 year study period the person would not have been selected for inclusion unless they were discharged and went on to have a subsequent admission.

Tracheostomy insertion can be performed for many reasons, such as managing severe upper airway obstruction, facilitating weaning from artificial ventilation, clearance of secretions or improving comfort. It may follow days or weeks of slow or failed attempts to wean from artificial ventilation or a period of critical illness. Often people have other comorbidities that can predispose to respiratory failure. It is estimated that only 3-5% of all tracheostomies are undertaken in babies and children due to the associated increased risks.[30] A recent UK review found that approximately 2% of all children admitted to a paediatric critical care underwent tracheostomy.[31]

In this study 50 new tracheostomy insertions were captured, after which people ultimately received LTV: 48/50 (96%) tracheostomy insertions were undertaken in an LTV centre and 32/50 (64.0%) occurred within 25 miles of the person’s home. The majority of children and young people were in paediatric critical care immediately before the decision was made to perform a tracheostomy (36/50; 72.0%).

Where the primary intention was to perform a tracheostomy for LTV (35/50; 70.0%)(Table 4.2), there was a clear record of how and when the decision was made for 23/35 (65.7%) people in that group. However, it was of note that the person’s GP was not included in the decision-making process in any instances.

Table 4.2 Indication(s) for tracheostomy insertion

	Number of people	%
Long-term ventilation	35	70.0
Difficult/unsafe airway	30	60.0
Absent/ineffective cough	8	16.0
Other	13	26.0
Total	**50**	

Answers may be multiple; n=50
Tracheostomy insertion questionnaire

In the 13 people where the reason was ‘other’ the reasons given were due to a failure to wean from non-invasive ventilation or upper airway problems. In 39/47 (83.0%) people (unknown in three) there had been at least one attempt to wean from ventilation prior to the tracheostomy. In 35/39 (89.7%) people this included a trial of extubation.

The anticipated level for invasive ventilation in the long-term varied considerably, with the majority of people being at level 2 or 3 (Table 4.3).

Table 4.3 Anticipated level of ventilation

	Number of people	%
High (level 1)	12	31.6
Severe (level 2)	9	23.7
Priority (level 3)	17	44.7
Subtotal	**38**	
Unknown	12	
Total	**50**	

Tracheostomy insertion questionnaire

Of the 38 people where the level of ventilation was known, the duration was unknown in four people, but of the remaining 34, 18/34 (52.9%) people had an expected need of 24/7 ventilator support.

For this group of 34, there was documentation of a multidisciplinary meeting to discuss the tracheostomy insertion and LTV in 24/34 (70.6%) people, and the implications of ongoing tracheostomy care at home had been discussed with the parent carers in 29/34 (85.3%). However, there was less certainty about how many conversations had occurred within the team making the decision to undertake tracheostomy insertion.

It was reported that parent carers were given written/other media information to view prior to the decision being made to undertake tracheostomy insertion and commence LTV for just 9/50 (18.0%) people. This information is widely available so there should not be any reason not to provide it.[20,34,35]

There were differences in opinion between clinicians and parent carers about whether a tracheostomy was appropriate for 5/31 (16.1%) people (unknown in 19). Given the complexity, gravity and long-term implications of such a decision, some disagreement may not be unexpected. Where this occurred it led to various methods of resolution including formal/informal multidisciplinary discussions, seeking a second opinion within the same hospital and involvement of an ethics committee (see Appendix 2).

Tracheostomies were performed as a scheduled procedure in 39/50 (78.0%) people and as urgent or emergency procedures in 11/50 (22.0%). In 44/50 (88.0%) people, the procedures were performed by ear, nose and throat surgeons. Importantly the operator was part of the multidisciplinary team that made the decision to commence LTV for 38/42 (90.5%) people (this was unknown in eight).

Consent was obtained by a consultant from 32/40 (80.0%) people and by a senior trainee or associate specialist doctor in a further 7/40 (17.5%) (unknown in 11).[34] Those undergoing the insertion were able to fully participate in the consent process in very few instances (3/50; 6.0%). In the remaining 47, it was generally because they were considered too young (34/47; 72.3%) (Table 4.4).

National guidance suggests that children and young people should always be included in decisions about their care when possible and that their level of inclusion should be documented.[29,34,35] Information about interventional procedures/surgery should also be presented in an accessible form for all ages and this is particularly important for people who may have specific problems with verbal or written communication.

Table 4.4 Reasons not able to participate in communication

	Number of people	%
Person was considered too young to participate in this discussion	34	72.3
Person lacked competence/capacity	10	21.3
Person had specific communication difficulties	7	14.9
Other	6	12.8
Subtotal	**47**	
Unknown	3	
Total	**50**	

Answers may be multiple, n=47
Tracheostomy insertion questionnaire

Communication and managing risk

People on LTV are a high-risk population, as possible difficult airways and chronic respiratory issues are often superimposed upon other complex comorbidities. One of the key methods of managing these risks is to prepare people, families and care teams in the community and in hospitals, who may not have expertise in LTV for dealing with emergency situations. Anticipating these needs can involve providing agreed and accessible emergency care plans as well as appropriate training.

The experience of service users and parent carers of communication with the LTV team was generally rated by them as good; 35/84 (41.7%) rated it as excellent and 65/84 (77.4%) rated it as 5-7 on the seven point scale used (five did not answer the question). Communication between LTV team members was rated as excellent by 31/81 (38.3%) service users and parent carers, and by 57/81 (70.4%) at 5-7 on the seven point scale used (Figure 4.1).

Emergency healthcare plans

Communication is particularly important when there is a transfer of responsibility, for example, on admission to, or discharge from, hospital. A personal care plan aids communication and has been recommended for all children and young people receiving LTV.[16] It has already been noted in Chapter 3 that health and social care professionals reported personal healthcare plans more likely to be in place for <18 year olds (102/126; 81.0%) than ≥18 year olds (43/77; 55.8%), where age was known.

Care plans should include important routine information as well as what to do in emergency. The 2018 NCEPOD report on chronic neurodisability included a principal recommendation that all people with complex needs be given the opportunity to develop a hand-held emergency healthcare plan (EHP) to facilitate communication.[1] EHPs aid rapid communication with the ambulance service and any acute admitting team. If changes are made families and carers should be fully aware.

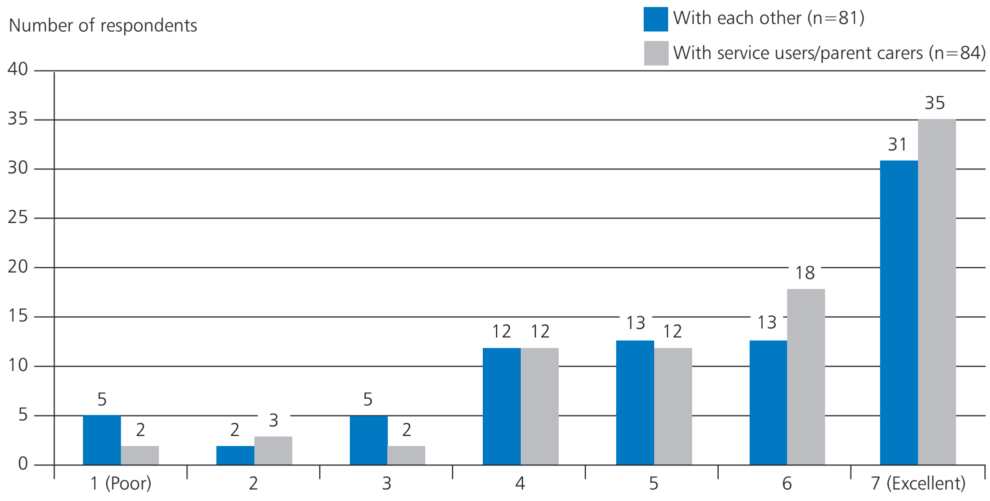


Figure 4.1 How well the team providing LTV care communicated as rated by service users and parent carers (n=81 for 'with each other', not answered in eight, and n=84 for 'with service users/parent carers', not answered in five)

Service user/parent carer survey

The need for emergency care planning to assist when escalation of care was required was re-enforced by comments made by clinicians in the one-to-one interviews.

> ***"All of our complex children have a detailed emergency plan as well as alerts from the London Ambulance Service, GPs and community teams. This provides excellent communication and ensures the child's needs are always met"***
>
> ***Consultant Nurse***

One clinician reported that in their organisation, the ambulance Trust and hospital Trust had access to shared notes and documentations. When a 999 call went out to the home of a child on LTV, the paramedics could alert the hospital to their arrival. This ensured the child was reviewed as soon as they reached the emergency department and even fast-tracked to critical care if needed (see Appendix 2).

> ***"We have an open access policy for our children for acute admission. Strangely, this has not only reduced our admissions but also reduced the overall length of stay. We do have very good communication links with our GPs and community teams which of course is very helpful"***
>
> ***Consultant Paediatrician***

However, feedback from some case reviewers indicated that provision of such plans and preparation of parent carers for emergencies was highly dependent on lead centres and regional networks. However, it was noted that some hospices had organised written plans and training in the absence of other providers putting these measures in place. From the service user and parent carer perspective, 58/80 (72.5%) parent carers had a written plan (escalation plan/ EHP) they could refer to and use if they needed urgent help (the question was not answered by nine respondents); all 58 parent carers knew who to contact. Training in preparation for common healthcare situations at home was reported to be received by 63/80 (78.8%) parent carers (not answered for nine), and 58/63 (92.1%) rated their confidence in dealing with urgent situations at 5-7, on the seven point scale used (Figure 4.2).

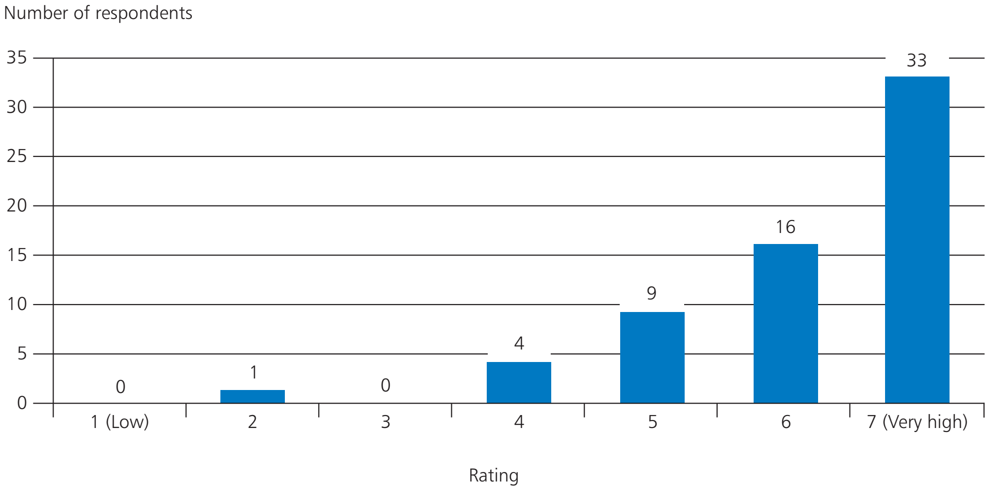


Figure 4.2 Confidence in dealing with urgent situations as rated by service users and parent carers (n=63, not answered in 26)

Service user/parent carer survey

There are similarities between EHPs and fast-track admission plans, but generally EHPs are more comprehensive and go beyond offering open access to hospital assessment and/or admission. They also contain information which guides immediate care in whatever location the person is based. EHPs may also contain details of decisions made in advance about escalation of care, with the inclusion of personal and parent carer preferences.

Data from community teams highlighted that 57/83 (68.7%) teams were aware of a fast-track admission plan or EHP for people they were caring for (it was unknown for 13 people). Where there was an EHP in place, the community team retained a copy for 53/56 (94.6%) people and where the data were available to comment, it was regularly updated for 49/51 (96.1%) people.

Admitting clinicians reported that 63/135 (46.7%) of the people admitted during the two-year study period had a fast-track admission plan in place (this was unknown in 17 people), and of these 55/63 (87.3%) stated it had been followed. Whilst numbers were small, Table 4.5 shows that a fast-track admission plan was more likely to be in place for people <18 years of age.

Admitting clinicians also reported that an EHP was in place for 52/75 (69.3%) people, but in a further 77 people it was either ‘unknown’ or said to be ‘not applicable’. Where a plan existed it had been communicated to parent carers in almost all cases (45/46; 97.8%), although unknown for six people).

CASE STUDY 6

Benefit of having an Emergency Healthcare Plan

> A teenager with very complex needs on home nocturnal ventilation had been admitted to hospital acutely unwell following a seizure. They were intubated and transferred to a critical care unit when a pneumonia developed. An agreed Emergency Healthcare Plan was in place and after a failed extubation attempt, re-intubation and discussion with the parents it was decided to transfer them for ongoing palliative care to a local hospice.
>
> *Case reviewers commented on the need for such plans to be in place more widely, and for care preferences to be clearly stated to guide clinicians when people present acutely. In this case the fact that there was a previously considered plan in place if critical care was felt to be no longer appropriate very much assisted the family and care team in their difficult decision-making.*

From the peer review of the case notes, an EHP was present in 23/149 (15.4%) sets of notes and had been used in the assessment process of 18/23 (78.3%) people. It is possible that the EHP might have been in electronic format or only constituted part of the records held by the person on LTV. For people in this study who had a new tracheostomy inserted to deliver LTV, an EHP was in place for 33/39 (84.6%) people (unknown, or not applicable for 11 people).

Table 4.5 Fast-track admission plan in place by age

	<18 years of age		≥18 years of age	
	Number of people	%	Number of people	%
Yes	55	55.6	8	22.2
No	44	44.4	28	77.8
Subtotal	**99**		**36**	
Unknown	8		7	
Total	**107**		**43**	

Admitting clinician questionnaire, n=150 unknown in two

Table 4.6 Arrangements in place to ensure that community staff could manage LTV safely

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Formal/structured training programme	13	76.5	11	31.4
Competency assessment	15	88.2	17	48.6
Informal training	7	41.2	18	51.4
None	1	5.9	5	14.3
Other	2	11.8	2	5.7
Subtotal	**17**		**35**	
Unknown	4		0	
NA	0		4	
Total	**21**		**39**	

Answers may be multiple
Organisational data

Training

Whilst personalised planning for the complex needs of LTV is important, there are generic competencies which all care team members require. There are examples of excellent training programmes available, but there is no recognised minimum training programme. Confidence in caring has been specifically highlighted by WellChild in their current strategy and includes the need to provide national training principles for parents, carers and professionals.[36]

There was a formal structured training programme to ensure community staff could manage LTV safely at home in 13/17 (76.5%) LTV centres in which <18 year olds were cared for, but only in 11/35 (31.4%) centres in which ≥18 year olds were cared for. A competency assessment process was available in 15/17 (88.2%) LTV centres in which care was provided to people <18 years of age (Table 4.6).

For parent carers, formal/structured training was provided in 16/21 (76.2%) LTV centres and competency assessments undertaken in 19/21 (90.5%) LTV centres in which people <18 years of age were cared for, compared with 11/39 (28.2%) and 18/39 (46.2%) LTV centres in which people ≥18 years were cared for.

Training to change a tracheostomy tube

Particular risks are associated with tracheostomy tube changes. Typically, first changes will always occur in a highly monitored environment in hospital. Complications which can occur include difficulty re-establishing an airway (unanticipated airway narrowing, bleeding or creating a false passage), air leaks (resulting in subcutaneous air and swelling) and as a worst case scenario, a critical loss of effective ventilation and/or oxygenation.[19]

CASE STUDY 7
Tracheostomy complications

A young person with complex neurodisability required an urgent abdominal operation. Postoperatively the young person required overnight CPAP to manage upper airway obstruction. A decision was made between critical care, surgery, the local LTV team and the person's family to perform a tracheostomy to commence invasive overnight ventilation. They had a good early recovery, but at the first tracheostomy change developed a false tract and pneumothorax, requiring readmission to critical care. A second tube change was subsequently performed in theatre and was uneventful.

Case reviewers commented that there is a need to be aware of the relatively common potentially serious problems associated with tracheostomies and the need for meticulous ongoing care.

There was considerable variation in the organisational data as to where routine care after first tracheostomy tube change was provided. Relatively, more teams providing care to ≥18 year olds stated that it occurred in critical care (26/46; 56.5%) and in those treating children and young people <18 years of age, there seemed to be a greater willingness for this to occur at home (42/50; 84.0%) (Table 4.7).[32,33]

> *"No clear guidelines of how many carers need to be with child. Awake supervision 7 nights per week is difficult to cover/ difficult for parents"*
>
> ***Health and social care survey***

Table 4.7 Where routine care after first tracheostomy tube changes was undertaken

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
At home	42	84.0	21	45.7
Outpatients	14	28.0	13	28.3
Inpatient ward	39	78.0	20	43.5
Critical care unit	19	38.0	26	56.5
Other	2	4.0	6	13.0
Subtotal	**50**		**46**	
Unknown	5		7	
Total	**55**		**53**	

Answers may be multiple
Organisational data

Managing risk when going home

A consensus between clinicians and care providers about how to manage the risk of common emergencies at home was reported by 107/161 (66.5%) healthcare professionals (Table 4.8).

Table 4.8 A consensus between clinicians/care providers about managing risk at home as reported by health and social care professionals

	Number of respondents	%
Yes	107	66.5
No	54	33.5
Subtotal	**161**	
Unknown	82	
Total	**243**	

Health and social care professional survey

Free-text comments from professionals highlighted that there was a variation in the expectations of what can, and cannot, be managed at home, the level of preparedness and supervision required by the care team (including parent carers) and on what an acceptable level of risk is.

> *"Particularly with regard to invasive ventilated children there appears to be an increasing expectation that 2:1 care is required at all times. This should be assessed on a case by case basis with consideration given to expertise and the competence of parents and also the care team from the service provider"*
>
> ***Health and social care survey***

Key Findings

35. Admitting clinicians reported that 63/135 (46.7%) of the people admitted during the two-year study period had a fast-track admission plan in place (unknown in 17), and of these 55/63 (87.3%) stated it had been followed – *Table 4.5*
36. 52/75 (69.3%) people in the sampled study population had an Emergency Healthcare Plan (EHP) in place, but a copy was only available in 23/149 (15.4%) sets of case notes
37. Training in preparation for common healthcare situations at home was reported to be received by 63/80 (78.8%) parent carers (not answered for nine), and 58/63 (92.1%) rated their confidence in dealing with urgent situations at 5-7, on the seven point scale used – *Figure 4.2*
38. There was a formal structured training programme to ensure community staff could manage LTV safely at home in 13/17 (76.5%) LTV centres in which <18 year olds were cared for, but only in 11/35 (31.4%) centres in which ≥18 year olds were cared for – *Table 4.6*
39. For parent carers, formal/structured training was provided in 16/21 (76.2%) LTV centres and competency assessments undertaken in 19/21 (90.5%) LTV centres in which people <18 years of age were cared for, compared with 11/39 (28.2%) and 18/39 (46.2%) LTV centres in which people ≥18 years were cared for
40. There was considerable variation in the organisational data as to where routine care after first tracheostomy tube change was provided. Relatively, more teams providing care to ≥18 year olds stated that it occurred in critical care (26/46; 56.5%) and in those treating children and young people <18 years of age, there seemed to be a greater willingness for this to occur at home (42/50; 84.0%) – *Table 4.7*
41. Where the primary intention was to perform a tracheostomy insertion for LTV (35/50; 70.0%), there was a clear record of how and when the decision was made for 23/35 (65.7%) people – *Table 4.2*
42. The implications of ongoing tracheostomy care at home had been discussed with 29/34 (85.3%) parent carers. It was reported that parent carers were given written/other media information to view prior to the decision being made to undertake tracheostomy insertion and commence LTV for just 9/50 (18.0%) people
43. Tracheostomies were performed as a scheduled procedure in 39/50 (78.0%) people with 11/50 (22.0%) reported as urgent or emergency procedures and 44/50 (88.0%) procedures were performed by ear, nose and throat surgeons. Importantly the operator was part of the multidisciplinary team that made the decision to commence LTV for 38/42 (90.5%) people (unknown in eight)
44. There were differences in opinion between clinicians and parent carers about whether a tracheostomy was appropriate for 5/31 (16.1%) people (unknown in 19)
45. For most people already established on ventilation (168/208; 80.8%), lead clinicians reported that LTV was started as ‘destination’ therapy i.e. with no immediate plan to discontinue – *Table 4.1*
46. Case reviewers and SAG members noted that there was a relative paucity of evidence on long-term outcomes from LTV to guide future decision-making
47. Many clinicians referenced the potential benefit of forming an independent expert panel, to which people with complex needs, awaiting LTV could be referred to peer review/mediation. A multidisciplinary team of clinical experts, legal representatives, service planners and lay members was proposed to assist with difficult decision-making

5

Acute admission pathway

Admission to hospital following initiation of long-term ventilation (LTV) can be for a variety of reasons and is a common event for many people. This chapter will describe a snapshot of these admissions based on information from parent carers, admitting clinicians and case reviewers. NB: Due to the different data sources the denominator will vary. To help this the data sources have been quoted throughout the chapter.

The Children's and Young People's Health Outcomes Forum has called for *"Better integration of care and services around the child and family"* and there are standards within the commissioning framework which identify this need, wherever the young person is being cared for.[37]

The Royal College of Paediatrics and Child Health's 'Facing the Future: Standards for children with ongoing health needs' has recommended that *"Service planners ensure systems are in place to monitor, review and improve the effectiveness and integration of local child health services. This must involve representatives of children and families and all agencies responsible for ensuring the health and wellbeing of children."*[29]

The NHS England Service Specification states that *"The MDT process must ensure that all children on the pathway have a Personal Care Plan (PCP) that includes, but is not restricted to, (a) escalation management in an emergency (b) list of essential equipment to take when out of the home environment (c) guidelines on communication with the ambulance service and local accident and emergency services (d) notification of utility companies (e) an equipment policy that includes service arrangements and guidance in the event of breakdown, (f) a clear plan for follow-up"* [17]

The general theme from these published documents is that an integrated care pathway should guide the person on LTV, and their family, and cross organisational boundaries to ensure consistent care and communication. Within a person's personal care plan there should be a consultant who provides leadership, assists in communication and ensures that the medical aspects of the person receiving LTV are being met.

Person profile: where and why they were admitted

Table 5.1 shows that people <18 years of age in this study were most commonly admitted to specialist paediatric tertiary centres for an acute admission. This often meant that they had to travel further to their lead centre for hospital care, as covered in Chapter 3.

Table 5.1 Type of hospital the person on LTV was admitted to for an acute admission, by age

	<18 years of age		≥18 years of age	
	Number of people	%	Number of people	%
District general hospital <500 beds	18	16.8	8	18.2
District general hospital ≥500 beds	27	25.2	7	15.9
University teaching hospital	19	17.8	27	61.4
Specialist paediatric tertiary centre	43	40.2	2	4.5
Total	**107**		**44**	

Admitting clinician questionnaire n=152; unknown in two

Specialist paediatric tertiary centres have Level 3 paediatric critical care onsite, with cots/beds and trained staff to provide ventilator support to babies and children of all ages. Most other LTV centres will have an adult/general critical care unit and variable competence and capacity to provide Level 1 or Level 2 paediatric critical care[38] or neonatal intensive care.[39]

At the time of admission, and where it could be answered by the admitting clinician, 86/135 (63.7%) people had been receiving LTV for ≥2 years with a range of two-23 years (it was unknown for 17 people). Most admissions (113/148; 76.4%) were unplanned, for urgent or emergency care, but 35/148 (23.6%) were planned for surgery, respiratory review or respite care (the reason was unknown in four people). For 73/150 (48.7%) people there was more than one underlying comorbidity which had led to their need for LTV (Table 5.2).

Table 5.2 Underlying comorbidities of the study population admitted acutely

	Number of people	%
Respiratory muscle weakness	80	53.3
Neurodisability	41	27.3
Skeletal deformity e.g. scoliosis	32	21.3
Central respiratory drive	30	20.0
Chronic respiratory condition	28	18.7
Upper airway obstruction	27	18.0
Obesity hypoventilation	6	4.0
Spinal cord injury	3	2.0
Other	22	14.7
Total	**150**	

Answers may be multiple; n=152
Admitting clinician questionnaire

Case reviewers stated that the admission had been directly related to LTV in 69/147 (46.9%) sets of notes reviewed (it was unknown in two people). This was more common for people <18 years of age (52/106; 49.1%), than ≥18 years of age (17/41; 41.5%).

Table 5.3 shows that people on LTV were most commonly admitted because they had increasing ventilator requirements (32/114; 28.1%) and/or problems with oxygenation (66/114; 57.9%) in the view of the case reviewers. In the detail of 52 people where there were 'other' contributing factors, 13/52 (25.0%) had increased secretion production and/or infection.

Table 5.3 Contributing factors to the admission to hospital

	Number of people	%
Problems with oxygenation (poor saturations, increased oxygen needs)	66	57.9
Changing or increasing ventilator requirements	32	28.1
Tracheostomy problems	9	7.9
Other	52	45.6
Subtotal	**114**	
None	33	
Unable to answer	2	
Total	**149**	

Answers may be multiple; n=114
Case reviewer data

Admitting clinicians reported that only 2/152 (1.3%) admissions might have been prevented, whereas case reviewers considered that 9/141 (6.4%) admissions could have been, where it could be assessed. In seven of these they considered that there were issues with improved respiratory care which could have been pre-empted and/or care delivered at home.

A majority (125/152; 82.2%) of people admitted to hospital on LTV were dependent on various other technologies, the most common of which were artificial feeding (87/125; 69.6%), use of a wheelchair (86/125; 68.8%) and cough assist devices (48/125; 38.4%) (Table 5.4).

Table 5.4 Equipment/technologies the person on LTV was dependent on

	Number of people	%
Artificial feeding – percutaneous endoscopic gastrostomy	87	69.6
Wheelchair	86	68.8
Cough assist devices	48	38.4
Artificial feeding – nasogastric tube	20	16.0
Devices to assist with communication, hearing or vision	14	11.2
Other	16	12.8
Total	**125**	

Answers may be multiple; n=125
Admitting clinician questionnaire

On admission 36/139 (25.9%) people (unknown in 13) went straight to critical care. This did not always relate to critical illness and in many non-specialist hospitals critical care was the only location where competences were appropriate to care for people on LTV.

These data present a profile of a population with complex chronic healthcare problems, many of whom were admitted for acute illness and/or because their respiratory/LTV requirements had increased.

CASE STUDY 8
Infrequent encounters with people on LTV

During admission to a local district general hospital a young child with cerebral palsy who was receiving invasive ventilation continued on their home ventilator on a paediatric ward and received physiotherapy and antibiotics for a chest infection. The young person deteriorated and a consultant anaesthetist was called to assist in the transfer to a general critical care unit and possible change of tracheostomy tube.

Case reviewers commented that the small DGH did not have paediatric respiratory physiotherapists available out of hours and that there would have been be a heavy reliance on the competences of the local general paediatric, anaesthesia and critical care teams. Since the number of such complex cases is small, it was likely that individual clinicians would encounter them infrequently, which made maintenance of (unit) knowledge and skills extremely challenging.

CASE STUDY 9
Frequent admissions to a district general hospital

A teenager with complex neurodisability and multiple comorbidities on non-invasive ventilation had experienced multiple admissions to a local district general hospital over an eight-month period, several had led to a transfer to paediatric critical care.

Case reviewers commented that this was a highly complex child who had frequent admissions to the local district general hospital. However, there was no obvious inclusion of the wider multidisciplinary team in the discharge documentation or the need for interventions that might prevent future admissions.

Arrival at hospital

Most people (67/126; 53.2%) arrived in hospital during the normal working day (Table 5.5). Of those arriving out of hours, 32/59 (54.2%) did so after 21.00 and before 06.00 when there was least likely to be a consultant in the hospital.

Table 5.5 Time of arrival at the hospital

	Number of people	%
08:00 - 17:59	67	53.2
18:00 - 07:59	59	46.8
Subtotal	**126**	
Unknown	26	
Total	**152**	

Admitting clinician questionnaire

The case notes showed that a consultant or senior specialist trainee (ST3+ or equivalent) were first to assess in 63/134 (47.0%) people, whilst a junior member of the team (basic grade, junior specialist trainee or junior nurse), were first to assess in 42/134 (31.3%) people, and it was unknown for 29 people.

Most people were assessed in an emergency department or an acute admissions area (82/149; 55.0%) but 23/149 (15.4%) were seen in a respiratory ward and 29/149 (19.5%) in a critical care area, it was unknown for 15 people. Data presented in Chapter 4 showed that fewer than half of the people admitted (63/135; 46.7%) had a fast-track admission plan in place, and where available this was followed in most cases.

Admission to hospital

Where the data were available, most people who were admitted had a high or severe (level 1 or 2) dependency on LTV (94/117; 80.3%). There were 55/117 (47.0%) people requiring 12 or more hours on the ventilator per day, and of this group, 44/55 (80.0%) people were fully ventilated for the whole day and night so had no ventilator-free period (Figure 5.1).

NB. There was a larger group of people dependent on invasive ventilation in the study due to planned oversampling.

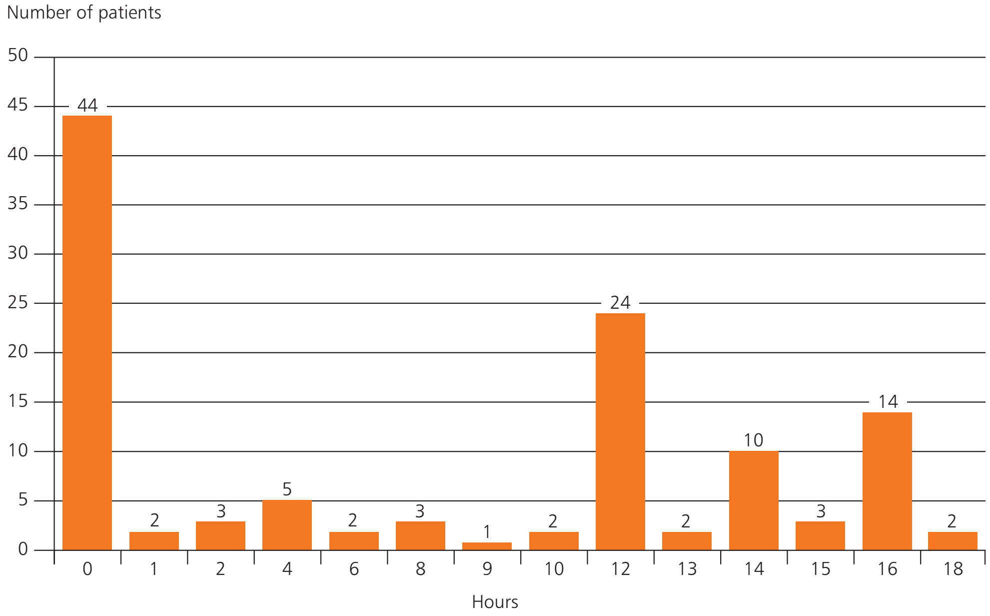


Figure 5.1 Number of hours of ventilator-free breathing per day (n=117, not answered in 35)

Admitting clinician questionnaire

In 38/142 (26.8%) people (unknown in 10), where the data were available to the admitting clinician, the ventilator dependency had changed from the person's usual LTV pattern prior to admission to hospital. In 33/145 (22.8%) people, problems with the LTV were apparent on admission (this was unknown in seven). LTV problems included changing/increasing ventilator requirements (11/33; 33.3%) and/or poor oxygen saturations (23/33; 69.7%); a further 3/33 (9.1%) people experienced tracheostomy problems. Table 5.6 shows that 52/105 (49.5%) people <18 years of age were admitted to a critical care area compared with 6/42 (14.3%) people ≥18 years of age. However, a higher percentage of people ≥18 years of age were admitted to specialist respiratory wards (16/42; 38.1%).

Admission location is an important factor, as it may indicate both the acuity and dependency of this group of people with complex needs. It may also relate to the competences of ward-based staff, and the facilities available for close observation and the care of people on LTV, who are highly dependent on technology. It is possible that the acuity of people <18 years of age was greater and this necessitated critical care admission more often. Specialist (adult) respiratory wards may also have an enhanced capability to care for people on LTV since increasing numbers of people in older years, suffering from COPD, are admitted there.

Table 5.6 Location of admission by age

	<18 years of age		≥18 years of age	
	Number of people	%	Number of people	%
Paediatric critical care unit	50	47.6	2	4.8
Specialist respiratory ward	22	21.0	16	38.1
Adult (general) critical care unit	2	1.9	4	9.5
Other	31	29.5	20	47.6
Subtotal	**105**		**42**	
Unknown	2		1	
Total	**107**		**43**	

Admitting clinician questionnaire; n=150, unknown in three

Comments from the clinician interview supported these findings. Clinicians stated that in their experience there was often variation in admission location between children and adults. They also commented that in their experience, children requiring LTV were more likely to be admitted to a critical care environment.

> ***"Having good relationships with ICU teams is imperative. Without this there will be delays in a child being admitted to ICU and nobody wants that. Our ICU Consultant colleagues have an excellent understanding of our LTV service and we very much value their support"***
>
> ***Consultant in Paediatric Medicine***

> ***"There can often be a very poor understanding of a child's condition and LTV requirements when they are admitted onto ICU. We need to educate ICUs on these complex young children and not just expect they know what to do"***
>
> ***Neuromuscular Care Advisor***

Location of admission was inappropriate for 13/149 (8.7%) people (unknown in three), in the opinion of the admitting clinicians. In 16/140 (11.4%) responses they stated that staffing was inappropriate for the person's needs due to the inadequate training and experience of both nursing and medical staff, in caring for people on LTV. Case reviewers also stated that in their opinion there were 6/100 (6.0%) people who should have been admitted to critical care but were not (although this could not be assessed for 49 people).

CASE STUDY 10
Ventilator familiarity

A young adult with a cerebral palsy was admitted to an adult respiratory ward due complications of their tracheostomy which was used for nocturnal ventilation. They required urgent transfer to adult critical care in another hospital due to unfamiliarity with the person's ventilator and limited ability to provide tracheostomy care on the ward.

Case reviewers stated that this scenario was not uncommon and hospital staff did not always having necessary training in the range of home ventilators in use.

> ***"We had a child admitted onto ICU with renal complications. The CCG agreed to fund the provision of care to continue while the child was in ICU but the ICU team refused to let the care team continue working with the child. The care package fell apart due to this and what should have been a four-week stay turned into a six-month stay"***
>
> ***Consultant Nurse***

To increase continuity of care, the Service Quality Standards recommend that arrangements are in place for the person's community team to work in different healthcare settings, including providing care in the acute hospital.[16] Case reviewers stated that the usual time was involved in the everyday delivery of care in 60/111 (54.1%) people, and there was evidence that members of the person's community team were involved in multidisciplinary team discussions 25/75 (33.3%) cases reviewed (Table 5.7).

Table 5.7 Members of the community care team were included in MDT discussions during this admission

	Number of people	%
Yes	25	33.3
No	50	66.7
Subtotal	**75**	
Unable to answer	32	
Not applicable	42	
Total	**149**	

Case reviewer data

Delays and transfers

Admitting clinicians reported that delays in the admission process occurred for just 9/144 (6.3%) people (unknown in eight). Where a delay occurred, this related mainly to finding an appropriate bed based on location and competencies. Case reviewers also considered that delay in initial assessment had occurred in 9/115 (7.8%) cases reviewed (unable to answer in 34).

Admitting clinicians reported that 14/149 (9.4%) people (unknown in three) required transfer. Of these, the distance from home to the transfer hospital was ≥25 miles for 10/14 (71.4%) people, and for 9/14 (64.3%) people this was for escalation of care. Case reviewers stated that the transfer was appropriate in all cases reviewed (14/14; 100%), but also in 5/14 (35.7%) that there were delays ranging between three and 48 hours. Problems organising the transfer related to bed availability in the destination hospital. There was no evidence of adverse consequences as a result of transfer, but on occasion there was a need to move people very long distances.

CASE STUDY 11
Paediatric critical care transfer

An infant was admitted to a local district general hospital with dropping oxygen saturation and thick secretions from a chest infection. A change in tracheostomy tube gave no improvement and they had experienced multiple similar admissions in the previous month, the last one being just one day before. On this occasion, after 72 hours, the infant was transferred to a regional tertiary centre for further care (a distance of 80 miles).

Case reviewers commented that it would have been important to try and prevent these multiple admissions but as the child was still very small and with complex problems, a paediatric critical care transfer was the only safe option.

Clinical review and ventilation leadership

The Royal College of Paediatrics and Child Health, the Royal College of Physicians and NHS England standards state the need for people admitted acutely to be reviewed by a senior clinicians within 14 hours of admission to hospital.[40,41,29] In this study, senior clinical review within 14 hours of admission, was documented in 54/77 (70.1%) people who were admitted as an emergency (Table 5.8).

Table 5.8 Senior clinical review within 14 hours of an emergency admission

	Number of people	%
Yes	54	70.1
No	23	29.9
Subtotal	**77**	
Unable to answer	13	
Total	**90**	

Case reviewer data combined with admitting clinician questionnaire to determine emergency admissions

Case reviewers found documentation that triage had recommended senior involvement in 69/110 (62.7%) people, but it was unknown in a further 39 cases. Whilst these findings may, in part, relate to poor record keeping, any audit of compliance relies on this information being documented.

Admitting clinicians stated that there had been daily consultant review for 105/142 (73.9%) people, but if senior trainees were also included in the analysis there was evidence of daily ST3+ review in 123/142 (86.6%) people (unknown in 10 people).

Case study 12 demonstrates that after transition from child to adult services clinical leadership may be a particular problem. The co-ordination of LTV care may fall to the person's GP, who may not have been involved in their care until this point. This theme was explored in Chapter 3.

CASE STUDY 12
Absence of community leadership for LTV care

A young adult with complex needs had been receiving non-invasive ventilation since their early teens and was admitted with a catheter related urinary infection to a surgical ward. Similar admissions had occurred previously. During this admission there was good evidence of a consultant urologist involvement but no mention of the ventilator settings or respiratory care. Other than the person's GP there was no obvious care leader at discharge.

Case reviewers stated that this highly complex person may have had care from other health professionals in the hospital and community. However, this information was missing from the clinical record and whilst the overall care was likely spread across several speciality areas there was no obvious leadership or co-ordination.

Table 5.9 Documentation in the case notes of clinical leadership whilst in hospital by reason for admission

	Directly related to LTV		Not related to LTV	
	Number of people	%	Number of people	%
Yes	41	66.1	41	54.7
No	21	33.9	34	45.3
Subtotal	**62**		**75**	
Unable to answer	8		4	
Total	**70**		**79**	

Case reviewer data

Case reviewers stated that there was evidence of clinical leadership during the admission in the case notes of 82/137 (59.9%) people, but it could not be determined in 12 cases. Clinical leadership was more likely to be apparent if the admission related directly to LTV care (41/62; 66.1% LTV admissions, 41/75; 54.7% non LTV admissions) (Table 5.9).

Respiratory care

On an acute admission to hospital, measurement of respiratory rate, oxygen saturation and documentation of inspired oxygen concentration (where applicable) are fundamental to the provision of safe care to all adults and children.[42,43] For people on LTV this assessment is of even greater importance.

Documentation of ventilator settings is also very important as treatment decisions may require changes to ventilator settings, however, these were not documented in 38/148 (25.7%) cases reviewed. Furthermore the respiratory rate was not documented in 18/135 (13.3%) cases and 13/133 (9.8%) cases had no mention of oxygen saturation (Table 5.10).

When people are admitted with a problem primarily related to ventilation or with low oxygen saturations, blood gas analysis is used to guide changes in ventilator settings. The case reviewers repeatedly commented that in addition to the absence of documentation of the basic respiratory parameters, blood gas analysis was frequently omitted when it should have been done. Evidence of blood gas analysis being undertaken was only available in 68/141 (48.2%) sets of case notes (Table 5.11). It was also relatively infrequent for a chest X-ray to be done, even for people whose primary reason for admission was a respiratory cause (64/141; 45.4%). Of the 64 people who has a chest X-ray, only 35/64 (54.7%) were admitted due to a primary respiratory cause.

Table 5.10 Documentation of ventilation assessments

	Respiratory rate		O2 saturation		Ventilation settings	
	Number of people	%	Number of people	%	Number of people	%
Yes	117	86.7	120	90.2	110	74.3
No	18	13.3	13	9.8	38	25.7
Subtotal	**135**		**133**		**148**	
Unable to answer	14		16		1	
Total	**149**		**149**		**149**	

Case reviewer data

Table 5.11 How the adequacy of respiratory support was assessed

	Number of people	%
Clinical assessment	129	91.5
Invasive assessment (blood gas)	68	48.2
Chest X-ray	64	45.4
Non-invasive CO2 assessment	7	5.0
Not assessed	6	4.3
Other	14	9.9
Subtotal	**141**	
Unable to answer	8	
Total	**149**	

Answers may be multiple; n=141
Case reviewer data

Previous admissions

An acute admission to the same hospital, in the previous six-months, had occurred in 68/145 (46.9%) people in the study, but this was unknown in seven people (Table 5.12): 56/68 (82.4%) were unplanned and in 46/68 (67.6%) people it was for an acute illness, 24/68 (35.3%) people had more than two admissions, and two had more than 10.

Table 5.12 An acute admission in the previous six-months

	Number of people	%
Yes	68	46.9
No	77	53.1
Subtotal	**145**	
Unknown	7	
Total	**152**	

Admitting clinician questionnaire

People who had been on LTV for <2 years were more likely to have had an unplanned admission in the previous six-months when compared to those receiving LTV for ≥2 years (Table 5.13).

Table 5.13 Previous unplanned admissions by length of time receiving LTV

	Number of people	%
<2 years	34	63.0
≥2 years	20	37.0
Subtotal	**54**	
Unknown	2	
Total	**56**	

Admitting clinician questionnaire

CASE STUDY 13

Delay to transfer

A young child requiring continuous ventilation via a tracheostomy presented to a local district general hospital with increased secretions and fever. This was the second acute admission in the previous six-months. The child developed a pneumonia and required more oxygen and increasing ventilator pressures over the next few days before being transferred to a regional paediatric critical care unit and discharged home six-weeks later after a slow recovery.

Whilst the case reviewers stated that the care was generally good in the referring unit, the transfer to the paediatric critical care unit should have occurred sooner. They considered that clearer advice should have been available in a joint fast-track admission plan as to when the ceiling for district general hospital care had been reached. When discharge was arranged there was a lack of multidisciplinary co-ordination to ensure both the care team and local hospital were fully informed about the change in the child's needs.

Discharge

Chapters 3 and 4 highlighted issues related to discharge planning and communication at discharge. Data from the admitting clinicians showed that 132/152 (86.8%) people were discharged to their normal residence or another LTV centre (13/152; 8.6%) at the end of the acute admission.

Adverse events

People were often admitted because they were acutely unwell and whilst the purpose of this review was not to report these incidents in any detail, it was of note that case reviewers reported 20/149 (13.4%) people as having an adverse event or complication during the acute admission.

Overall quality of care

The grading system below was used by the case reviewers to provide a general summary of the quality of LTV care received during the acute admission.

Good practice: A standard that you would accept from yourself, your trainees and your institution.
Room for improvement: Aspects of **clinical** care that could have been better.
Room for improvement: Aspects of **organisational** care that could have been better.
Room for improvement: Aspects of both **clinical and organisational** care that could have been better.
Less than satisfactory: Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution.
Insufficient data: Insufficient information submitted to NCEPOD to assess the quality of care.

Figure 5.2 shows the overall quality of LTV care was stated to be good in 44/144 (30.6%) cases reviewed. Room for improvement was identified in clinical care alone in 44/144 (30.6%) cases, organisational care alone in 10/144 (6.9%) cases and both clinical and organisational care in 37/144 (25.7%) cases. In 9/144 (6.3%) cases reviewed care was reported to be less than satisfactory.

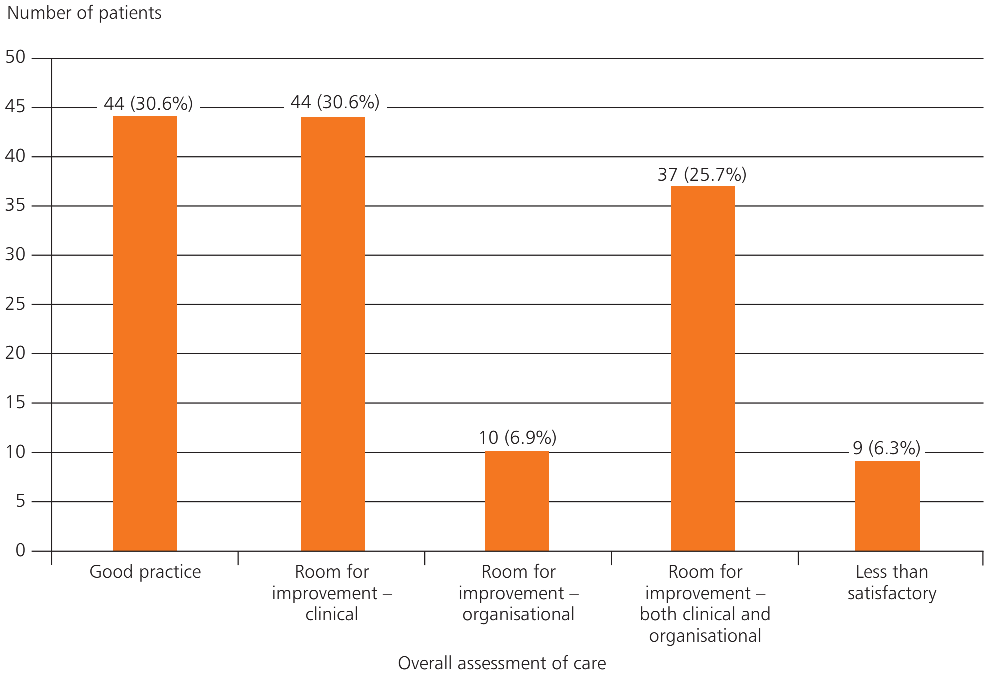


Figure 5.2 Overall quality of care in for the acute admission n=144, unable to assess in five

Case reviewer data

Case reviewers identified deficiencies in the clinical monitoring of 58/142 (40.8%) people (this was unknown for seven people). They also stated that there were problems with day-to-day care that could be improved in 47/141 (33.3%) people (this was unknown in eight people). Free-text comments from this group of 47 mainly highlighted poor information sharing or documentation (19/47; 40.4%) and/or multidisciplinary involvement (16/47; 34.0%).

In addition, lead clinicians (n=229) and community clinicians (n=96) were also asked in their questionnaires about overall quality of care given to people on LTV, irrespective of whether they were admitted to hospital or not. These data showed that:

- Lead clinicians identified areas for improvement in the care of 79/213 (37.1%) people (this was unknown in 16 people), which included:
    - Access to specialist beds, the absence of which led to delays in admission
    - Poor access to physiotherapy and psychology services in the community
    - Improved knowledge and skills of teams to which people are admitted to when acutely unwell
- Community clinicians identified areas for improvement in the care of 32/76 (42.1%) people (this was unknown in 20 people), which included:
    - Care arrangements after transition to adult services
    - Deficiencies in skills and training
    - A lack of clarity about funding arrangements

Key Findings

48. Most admissions (113/148; 76.4%) were unplanned, for urgent or emergency care. Planned admissions (35/148; 23.6%) were for surgery, respiratory review or respite care, according to case reviewers
49. People on LTV were most commonly admitted because they had increasing ventilator requirements (32/114; 28.1%) and/or problems with oxygenation (66/114; 57.9%) in the view of the case reviewers –*Table 5.3*
50. On admission 36/139 (25.9%) people went straight to critical care. This did not always relate to critical illness and in many non-specialist hospitals, critical care was the only location where competences were appropriate to care for people on LTV
51. At the time of admission, and where it could be answered, 86/135 (63.7%) people had been receiving LTV for ≥2 years with a range of 2 -23 years
52. 38/142 (26.8%) people, where the data were available to the admitting clinician, the ventilator dependency had changed from the person’s usual LTV pattern prior to admission to hospital
53. Senior clinical review within 14 hours of admission was documented for 54/77 (70.1%) people who were admitted as an emergency – *Table 5.8*
54. Case reviewers stated that 60/111 (54.1%) people had their usual team involved in multidisciplinary team discussions whilst as an inpatient, and evidence that members of the person’s community team were involved in 25/75 (33.3%) cases reviewed – *Table 5.7*
55. Case reviewers stated that there was evidence of clinical leadership during the admission in the case notes of 82/137 (59.9%) people, but it could not be determined in 12 cases
56. Clinical leadership was more likely to be apparent if the admission was related directly to LTV care (41/62; 66.1% LTV admissions, 41/75; 54.7% non LTV admissions) – *Table 5.9*

57 An acute admission to the same hospital, in the previous six-months, had occurred in 68/145 (46.9%) people in the study, but was unknown in seven people. The majority of these (56/68; 82.4%) were unplanned and in 46/68 (67.6%) people it was for an acute illness – *Table 5.12*

58. People who had been on LTV for <2 years were more likely to have had an unplanned admission in the previous six-months when compared to those receiving LTV for ≥2 years – *Table 5.13*

59. 52/105 (49.5%) people <18 years of age were admitted to a critical care area compared with 6/42 (14.3%) people ≥18 years of age. However, a higher percentage of people ≥18 years of age were admitted to specialist respiratory wards (16/42; 38.1%) – *Table 5.6*

60. Respiratory rate at admission was not documented in 18/135 (13.3%) sets of case notes – *Table 5.10*

61. Oxygen saturation at admission was not documented in 13/133 (9.8%) sets of case notes – *Table 5.10*

62. Ventilator settings at admission were not documented in 38/148 (25.7%) sets of case notes – *Table 5.10*

63. Blood gas analysis was documented in 68/141 (48.2%) sets of case notes – *Table 5.11*

64. 64/141 (45.4%) people had a chest X-ray, of which 35 were admitted due to a primary respiratory cause – *Table 5.11*

65. Clinicians who were interviewed stated that in their experience children requiring LTV were more likely to be admitted to a critical care environment

66. Admitting clinicians reported that in their opinion the location of admission was inappropriate for 13/149 (8.7%) people

67. In 16/140 (11.4%) responses admitting clinicians stated that staffing was inappropriate for the person's needs due to the inadequate training and experience of both nursing and medical staff, in caring for people on LTV

68. 6/100 (6%) people should have been admitted to critical care but were not according to the case reviewers

69. Overall quality of care was stated to be good in 44/144 (30.6%) cases reviewed. Room for improvement was identified in clinical care alone in 44/144 (30.6%) cases, organisational care alone in 10/144 (6.9%) cases and both clinical and organisational care in 37/144 (25.7%) cases. In 9/149 (6.3%) cases reviewed care was reported to be less than satisfactory– *Figure 5.2*

6

Respiratory equipment and routine assessment

This chapter presents data on the respiratory equipment and ongoing assessments needed to treat people on long-term ventilation (LTV). NB: Due to the different data sources the denominator will vary. To help this the data sources have been quoted throughout the chapter.

Despite the many different diagnoses and the age range of people in this study, all had one requirement in common: the need for respiratory support. As already described, the people included in the study were heavily dependent on equipment and technologies in addition to ventilation, reflecting the complex nature of their underlying conditions. The equipment required to provide safe and effective care for a person on LTV will vary depending on the level of ventilator dependency. For example, a person who is able to breathe independently all day and only requires overnight support will, in general, not require a backup ventilator, whereas this is mandatory for those dependent on ventilation at all times.[16]

Figure 6.1 illustrates that the equipment available to children and young people treated with ventilation was inconsistent. This variation was particularly important for those with a higher level requirement for ventilation (level 2 and 3), where backup arrangements are designed to ensure they can be treated safely in the event of equipment or power failure. Of the level 2 or 3 ventilator dependent people, 72/85 (84.7%) had a backup ventilator available and 48/85 (56.5%) had a ventilator battery pack.

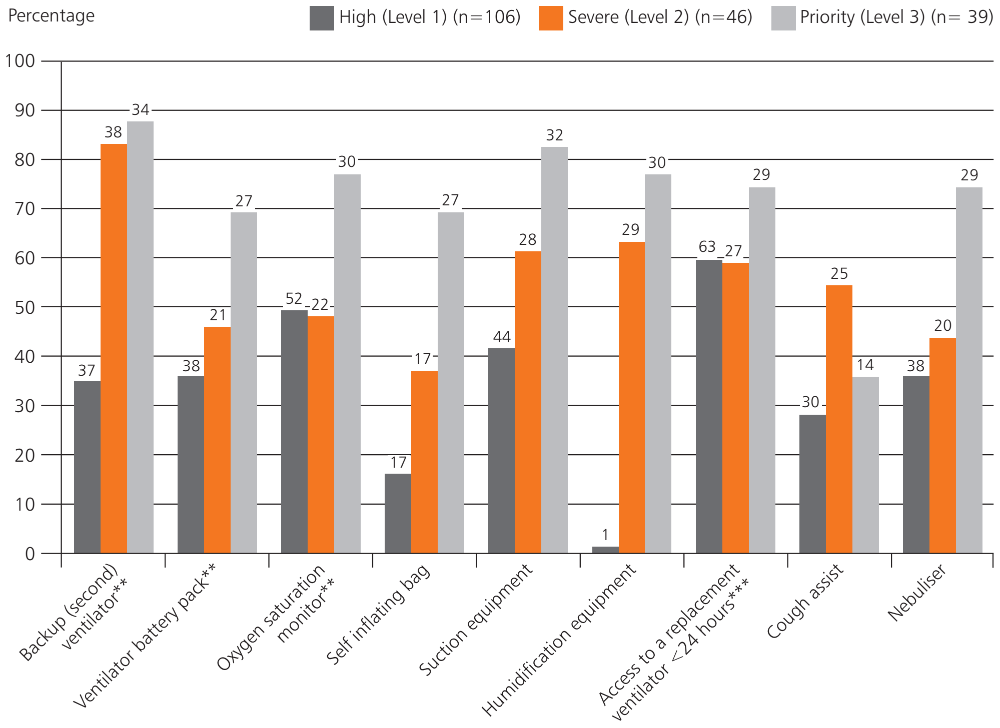


Figure 6.1 Equipment available by level of dependency (label = number of people)
Answers may be multiple; n=191
Lead clinician questionnaire

***requirement for level 2 or 3 ventilator dependency ***requirement for level 1 ventilator dependency*[16]

Focus groups with the parent carers of people on LTV revealed that equipment was a major source of concern. There appeared to be high levels of trust in specialist LTV care received in hospital. However, views about LTV equipment used at home were more mixed. Participants appreciated being able to receive complex care in the home, but it was often unclear which service was responsible for maintaining the equipment. In some cases this was linked to budget restrictions. The same issues were apparent regarding supplies for LTV equipment, with parent carers having to take responsibility for equipment, and sometimes having to drive to services themselves to pick up parts.

Health and social care professional survey data showed that professionals involved in LTV provision rated equipment services positively, 18/181 (9.9%) rated them as excellent and 127/181 (70.2%) at a level of 5-7 on the seven point scale used (Figure 6.2). The most commonly identified areas for improvement in relation to equipment services were training (98/233; 42.1%), competency (115/233; 49.4%), and out of hours support (107/233; 45.9%), (see Table 6.2, where answers may be multiple and the question was not answered in 10).

Data presented in Table 6.1 shows that organisations from which a response was received, reported that equipment services could be improved for all age groups.

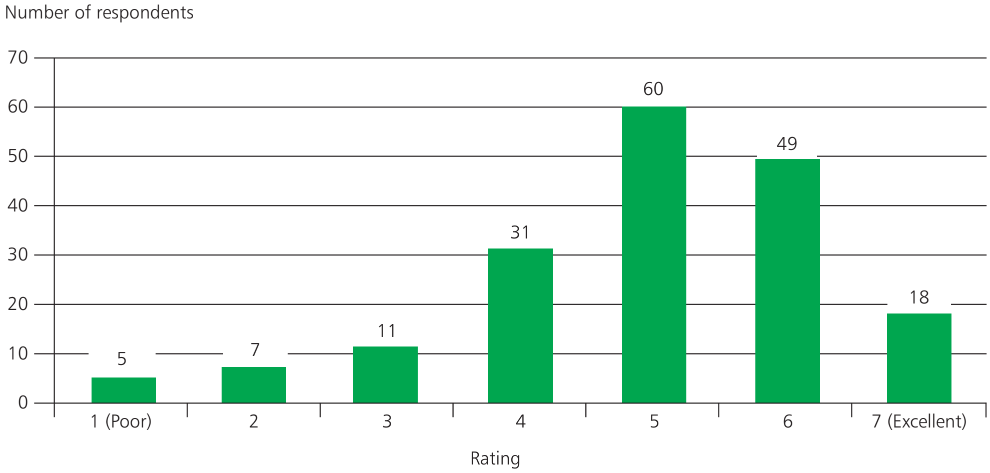


Figure 6.2 Rating of equipment services for young people receiving LTV as rated by health and social care professionals (n=181, not answered in 62)
Health and social care professional survey

Table 6.1 Aspects of equipment provision that could be improved by age

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Yes	14	73.7	20	60.6
No	5	26.3	13	39.4
Subtotal	**19**		**33**	
Unknown	2		7	
Total	**21**		**40**	

Organisational data

Interviews with healthcare professionals identified the importance of providing clinical and technical support for people on LTV and their families. Models of service that worked well included the provision of outreach services by the hospital team or WellChild nurses who were available in some areas (see Appendix 2).

> ***"Having the ability to see children at home means we can change their treatment if needed when they are unwell or their condition progresses. This might mean changes to their ventilator or cough assist but without doubt it prevents hospital admission. If I could not do this we would have to admit children to hospital and that's not good for anyone"***
>
> ***Specialist Physiotherapist***

Interviewees also identified a great deal of variation in how equipment was procured and purchased across the services, for example, a block contract agreement or tariff based procurement. For hospitals where there was no agreed equipment pathway, an individual patient request form (IPRF) had to be completed every time a device was needed. Individual services often dealt with a number of service planners/commissioners. It was reported that no consistent process was applied by different commissioners. Comments from the health and social care professional survey about areas of respiratory equipment provision that could be improved, included:

- Clarity on ventilator servicing arrangements (20 responses)
- Clarity on funding or commissioning arrangements (20 responses)
- Clarity on arrangements for accessing disposables in the community (16 responses)
- Access to cough assist devices (7 responses)

However, the most common area identified for improvement in equipment services, was not respiratory equipment but wheelchair services (42 responses).

> ***"The provision of a nurse has led to responsive community based support providing care outside of the hospital. This has allowed children to be weaned from ventilation which would never have been possible otherwise"***
>
> ***WellChild Nurse***

Although each individual person requires a bespoke equipment package tailored to their needs, these data suggest that some standardisation of the approach to ordering and purchasing of equipment has the potential to improve the quality of LTV services. Table 6.2 shows that there were 58/233 (24.9%) areas highlighted in the health and social care professional survey that related to standardisation of the ventilator and 68/233 (29.2%) areas related to community supply of disposables. This table also shows the issues raised with regard to ventilator equipment. It was of note that issues related to equipment were also raised in the case note reviews for 20/149 (13.4%) people.

Table 6.2 Areas highlighted for improvement with regard to ventilator equipment as reported by health and social care professionals

	Number of respondents	**%**
The maintenance competences of carers	115	49.4
Out of hours support	107	45.9
Providing training required for use of LTV equipment	98	42.1
Maintenance of equipment – in the community	75	32.2
Community supply of disposables	68	29.2
Lack of standardisation of ventilator provided	58	24.9
Storage of disposables	43	18.5
Maintenance of equipment – in hospital	19	8.2
Other	59	25.3
Subtotal	**233**	
Not answered	10	
Total	**243**	

Answers may be multiple; n=233
Health and social care professional survey

> ***"There is such inconsistency regarding funding agreements. We cover multiple CCGs and each has their own opinion. This affects access to equipment and time for procurement depending where you live. Why can't we have a standardised approach? This is the only way we can ensure consistency"***
>
> ***Paediatric Respiratory Clinical Nurse Specialist***

Community arrangements for respiratory support

As noted in Chapter 2, improved access to a full multidisciplinary team, including community care, was identified as an area that required improvement. Access to physiotherapy was identified as a specific need and this was reflected in the community data where 70/89 (78.7%) people had access to a physiotherapist (Table 6.3).

Table 6.3 Therapy access in the community

	Number of people	%
Occupational therapist	72	80.9
Nutritional support/dietitian	72	80.9
Physiotherapist	70	78.7
Speech and language therapist	62	69.7
Tracheostomy specialist	24	27.0
Other	24	27.0
Subtotal	**89**	
Unknown	7	
Total	**96**	

Answers may be multiple; n=89
Community team clinical questionnaire

Figure 6.3 shows who was responsible for community care provision, and highlights how the responsibility for care at home fell mostly on parent carers and families (85/96; 88.5%).

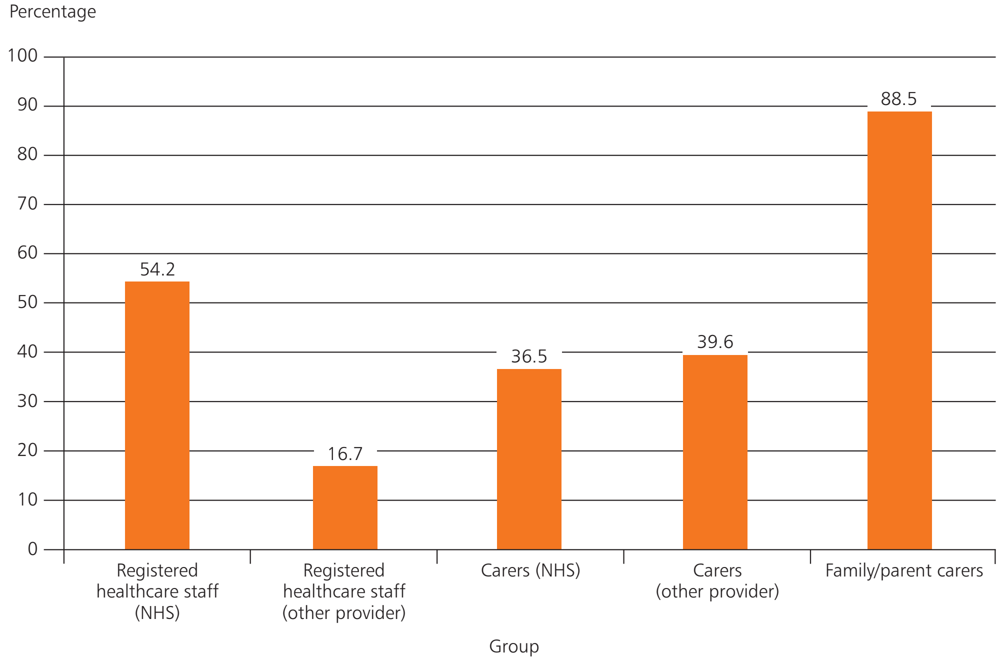


Figure 6.3 Responsibility for community care provision

Answers may be multiple; n=96

Community team clinical questionnaire

In the community, 80/91 (87.9%) teams had received training in ventilator use, unknown for five teams. The community team was responsible for daily ventilator checks in only 27/91 (29.7%) people and there were 52/91 (57.1%) people for whom parent carers had specific daily ventilator responsibility.

There was an equipment policy for LTV in the majority of hospitals (48/57; 84.2%) (Table 6.4), which generally specified what the arrangements were for ventilator servicing. However, organisational data in Table 6.5 shows that there was often no routine contract for ventilator servicing or maintenance.

Table 6.4 Equipment policy for LTV in hospitals

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Yes	18	90.0	30	81.1
No	2	10.0	7	18.9
Subtotal	**20**		**37**	
Unknown	1		3	
Total	**21**		**40**	

Organisational data

Table 6.5 Equipment service/maintenance contract for ventilator equipment in the community

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
Yes	13	68.4	26	70.3
No	6	31.6	11	29.7
Subtotal	**19**		**37**	
Unknown	2		3	
Total	**21**		**40**	

Organisational data

Community team clinical questionnaire data highlighted 13/83 (15.7%) people in the community where a ventilator service contract was not in place.

Outpatient respiratory assessment

Improving access to services was highlighted as an important area by people on LTV and parent carers. Flexible arrangements for review are required due to the complex nature of the conditions being treated with LTV. Some people will find it difficult to attend the hospital, or will have care needs that mean that a standard outpatient environment is not appropriate for them.

Table 6.6 shows that arrangements for routine outpatient assessment and review mainly took place in an outpatient clinic setting or as a ward-based review for all ages. Review in the home was possible in 20/40 (50.0%) services for people ≥18 years of age and for 7/20 (35.0%) services for people <18 years of age. For clinically unstable people, both emergency department attendance and direct ward admission were pathways used in the majority of services. Importantly, an emergency call to the GP was a common part of the pathway outside of routine reviews.

The frequency of review required depends on how long ventilation has been established, the stability of the person's underlying condition and any recent clinical changes or deterioration. If stable, regular review is required to adjust ventilator settings, in particular when a child grows. Data from the organisational questionnaires showed that when clinically stable, review was often planned for every six or twelve months (Table 6.7).

Table 6.6 How outpatient review for people on LTV was provided

	Routine review (stable)				Clinically unstable			
	<18 years of age		≥18 years of age		<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%
Outpatient clinic	17	85.0	37	92.5	13	65.0	36	90.0
Within ward environment	15	75.0	19	47.5	15	75.0	23	57.5
Home assessment	7	35.0	20	50	7	35.0	21	52.5
Defined urgent care pathway	0	0	0	0	9	45.0	5	12.5
Emergency department attendance	0	0	0	0	17	85.0	30	75.0
Direct ward admission	0	0	0	0	9	45.0	25	62.5
Emergency call to GP	0	0	0	0	11	55.0	22	55.0
Other	4	20.0	7	17.5	1	5.0	0	0.0
Total	**20**		**40**		**20**		**40**	

Answers may be multiple
Organisational data

Table 6.7 Frequency of outpatient review for those clinically stable on LTV

	<18 years of age		≥18 years of age	
	Number of hospitals	%	Number of hospitals	%
At least every six months	10	55.5	24	60.0
At least annually	7	38.9	13	32.5
Other	1	5.5	3	7.5
Subtotal	**18**		**40**	
Unknown	2		0	
Total	**20**		**40**	

Organisational data

Table 6.8 lists the ways that healthcare practitioners involved in delivery of care assessed the adequacy of ventilation in the service they provided. The most common assessment was clinical review (116/124; 93.5%), followed by sleep studies (101/124; 81.5%). A model of care that included access to home sleep studies was something that parent carers highlighted as being important to them (see Chapter 2 and Appendix 2).

Table 6.8 How the adequacy of ventilation was assessed once people were established on LTV as reported by health and social care professionals

	Number of respondents	%
Clinical review	116	93.5
Sleep studies	101	81.5
Blood gas analysis/non-invasive monitoring of carbon dioxide	91	73.4
Respiratory function tests	55	44.4
Other	26	21.0
Subtotal	**124**	
NA – not part of job role	82	
Not answered	37	
Total	**243**	

Answers may be multiple; n=124
Health and social care professional survey

Key Findings

70. Clinical review was the most common assessment of the adequacy of ventilation (116/124; 93.5%) – Table 6.8
71. 72/85 (84.7%) people, who were level 2 or 3 ventilator dependent, had a backup ventilator available and 48/85 (56.5%) had a ventilator battery pack, according to the lead clinicians – *Figure 6.1*
72. Health and social care professionals most commonly identified areas for improvement in relation to equipment services as training (98/233; 42.1%), competency (115/233; 49.4%), and out of hours support (107/233; 45.9%) – *Table 6.2*
73. Equipment issues were also identified in the case notes of 20/149 (13.4%) people
74. There were 58/233 (24.9%) areas highlighted in the health and social care professional survey that related to standardisation of the ventilator and 68/233 (29.2%) areas related to community supply of disposables – *Table 6.2*
75. In the community, 80/91 (87.9%) teams had received training in ventilator use, unknown for five teams. The community team was responsible for daily ventilator checks for only 27/91 (29.7%) people and there were 52/91 (57.1%) people where parent carers had specific responsibility
76. There was an equipment policy for LTV in the majority of hospitals (48/57; 84.2%), which generally specified what the arrangements were for ventilator servicing – Table 6.4
77. Community team clinical questionnaire data highlighted 13/83 (15.7%) people in the community where a ventilator service contract was not in place.
78. The responsibility for care at home fell mostly on parent carers and families (85/96; 88.5%) – *Figure 6.3*

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Glossary

Term		Definition
Bilevel positive airway pressure	BPAP	It is a type of non-invasive ventilation (NIV) or breathing support. It provides assistance when breathing in and breathing out.
Cerebral palsy		Cerebral palsy is the name for a group of lifelong conditions that affect movement and co-ordination, caused by a problem with the brain that occurs before, during or soon after birth.
Classification of interventions and procedures	OPCS	This is an information standard used by healthcare providers to standardise types of healthcare operations and procedures people can have
Congenital central hypoventilation syndrome	CCHS	This is a disorder that affects normal breathing. People with this disorder take shallow breaths (hypoventilate), especially during sleep, resulting in a shortage of oxygen and a build-up of carbon dioxide in the blood.
Continuous positive airway pressure	CPAP	This is a type of non-invasive ventilation (NIV) or breathing support which applies mild air pressure on a continuous basis to keep the airways continuously open in people who are able to breathe spontaneously on their own.
Cough assist devices		These are machines which help clear secretions or 'phlegm' from the lungs. The cough assist is usually given by a mask over the mouth and nose.
District General Hospital	DGH	In the context of this study it covers all non (LTV) specialist hospitals where acute care may be delivered even if it is initial emergency care. In contrast to the LTV centres these hospitals would not generally be those leading routine/normal decision making, support and review of a patient’s ventilator care.
Down’s syndrome		A genetic condition caused by the presence of an extra chromosome in a baby’s cells.
Invasive ventilation		A tube in a person’s trachea (‘windpipe’) or in the longer term a tracheostomy may be used during acute respiratory failure, weaning and for chronic respiratory failure when non-invasive ventilation is impossible to manage correctly.
Long-term ventilation	LTV	Ventilation provided every day for three months (invasive and non-invasive) where the intention is/was to maintain the person at home on continued ventilatory support (not home oxygen).
Long-term ventilation centre		A centre in which people were provided with the normal decision-making, support and review of their ventilator care
Long-term ventilation service		Covers all aspects of care delivered within the LTV pathway. This includes the LTV centre, step down service, respite care, home support, acute care (wherever it is delivered) and those that commission/plan the service. It includes all professionals that support these services.

Muscular atrophy		This is a decrease in the mass of the muscle; it can be a partial or complete wasting away of muscle, and is most commonly experienced when persons suffer temporary disabling circumstances such as being restricted in movement and/or confined to bed or wheelchair.
Muscular dystrophy	MD	This is a group of muscle diseases that result in increasing weakening and breakdown of skeletal muscles over time. The disorders differ in which muscles are primarily affected, the degree of weakness, how fast they worsen, and when symptoms begin.
Nasal cannula/prong		A lightweight tube which splits into two prongs which are placed in the nostrils to deliver a mixture of air and oxygen for non-invasive ventilation.
Nasogastric tube	NG tube	This is a narrow tube passed into the stomach via the nose. It is used for short- or medium-term nutritional support.
Non-invasive ventilation	NIV	This refers to the provision of ventilatory support through the person's upper airway using a mask or nasal cannula.
Obstructive sleep apnoea	OSA	This causes breathing to repeatedly stop and start during sleep. This occurs when the throat muscles intermittently relax and block the airway.
Percutaneous endoscopic gastrostomy	PEG	This is a medical procedure in which a tube is passed into a person's stomach through the abdominal wall, most commonly to provide a means of feeding.
Tracheostomy		A medical procedure that is either temporary or permanent that involves creating an opening in the neck in order to place a tube into a person's windpipe to allow air to enter the lungs.
Ventilator dependency levels		• High (Level 1): Is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm • Severe (Level 2): Requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support • Priority (Level 3): This includes those with no respiratory drive at all who are dependent on ventilation at all times, including those with no respiratory drive when asleep or unconscious who require ventilation and one-to-one support while asleep, as disconnection would be fatal.

Appendices

Appendix 1 – Line of sight between the recommendations, key findings and existing supporting evidence

Suggested target audiences to action the recommendations are listed in italics under each one. The primary target audience/audiences are in bold. *The term 'healthcare professionals' includes, but is not limited to, doctors, surgeons, nurses, general practitioners, physiotherapists, speech and language therapists and occupational therapists*		# is the number of the supporting key data in the report	Associated guidelines and other related evidence
1	**Ensure service planning/commissioning of integrated care pathways for long-term ventilation services includes formal contract arrangements and local standardisation where possible.** These arrangements should bridge child and adult health as well as social care services, respite care and any other partnerships relevant to the local network. Networks should map commissioning arrangements to ensure integration and consistent standards of care and national commissioners should provide a forum to ensure that long-term ventilation provision is considered collectively and delivered to agreed standards. ***Target audiences*** ***Service Planners/Commissioners (National and Local)*** *with support from Trust/Health Board Executive Committees, Social Care, Primary Care, Education, Respite/Hospice Care, Healthcare Professionals in all hospitals (including those that are not LTV centres) and Third Sector Organisations*	**CHAPTER 2 – PAGE 29** #3. Health and social care survey data highlighted a number of improvements that could be made to LTV services, as well as areas of good care, which were often similar – Table 2.3 including: • Access to the wider multidisciplinary team - worked well 138/219 (63.0%) and could be improved 115/219 (52.5%) • Access to services - worked well 35/219 (16.0%) and could be improved 70/219 (32.0%) • Improved clinical knowledge and skills about LTV - worked well 26/219 (11.9%) and could be improved 48/219 (21.9%) • Respite/hospice care - worked well 21/219 (9.6%) and could be improved 15/219 (6.8%) **CHAPTER 3 – PAGE 37** #18. Commissioning of LTV services was rated 5-7 on a seven point scale by 68/167 (40.7%) health and social care professionals – *Figure 3.2* **CHAPTER 3 – PAGE 38/39** #19. Data from the LTV community team clinical questionnaire showed that healthcare was commonly the primary source of funding (73/85; 85.9%). There were 36/85 (42.4%) people who received social care funding, and only 15/85 (17.6%) people had a personal healthcare budget in place – *Table 3.2* #20. Organisational data showed that service planning/commissioning for LTV was formalised in 13/19 (68.4%) LTV centres in which care was provided to people <18 years of age, and 25/37 (67.6%) for people aged ≥18 years of age. There was considerable variation in what was commissioned, with very little respite care (9/54; 16.7%) – *Table 3.3* **CHAPTER 3 – PAGE 39** #22. The absence of respite care was re-enforced by data from the health and social care professional survey. There was a marked difference between the two age groups – *Figure 3.3*	The Quality Review Service (formally West Midlands Quality Review Service) LTV Quality Standards: https://qualityreviewservicewm.nhs.uk/standards/page/2/ NHSE E07 – Service specification- Level 3 - Paediatric Critical Care (PCC) https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf NHSE Paediatric Critical Care and Surgery in Children Review https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup – register to access

2	**Ensure that it is possible to identify all people who are receiving long-term ventilation.** a) Locally this should be achieved by implementing/maintaining a database as soon as possible b) Nationally this should be achieved by developing procedure codes for long-term ventilation to bring together the local data collection and support a national database to quantify service provision and facilitate quality improvement ***Target audiences*** ***LTV Services and NHS Digital, NHS England, NHS Improvement, NHS Scotland, NHS Wales Informatics Service, Northern Ireland Statistics and Research Agency*** *with support from Trust/Health Board Executive Committees, Social Care and Service Planners/Commissioners*	**CHAPTER 1 – PAGE 16** #1. There is no Classification of Interventions and Procedures (OPCS) code for LTV, and the way hospitals record the details of people on LTV varies **CHAPTER 1 – PAGE 19** #2. 3,061 people, from 113 hospitals within 94 Trusts/Health Boards were reported to be on LTV during the study period. This was likely to be an under-representation due to coding and data returns **CHAPTER 3 – PAGE 37** #10. An annual audit of people on LTV was undertaken in 32/63 (50.8%) LTV centres – *Table 3.1*	NHSE Paediatric Critical Care and Surgery in Children Review https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup – register to access
3	**Ensure efficient care planning and discharge by providing a multidisciplinary team as part of an integrated care pathway.** This team should work across community and hospital networks of care for child and adult long-term ventilation services, have an identified clinical lead and include as a minimum: a) Medical and nursing staff b) Physiotherapy c) Speech and language therapy d) Psychology Where applicable e) A specialist in tracheostomy care f) Palliative care/hospice care g) Local service planners/commissioners ***Target audiences*** ***Service Planners/Commissioners and Trust/Health Board Executive Committees*** *with support from LTV Services, Social Care and Hospice/Respite Care, Psychology and Palliative Care*	**CHAPTER 2 – PAGE 29** #3. Health and social care survey data highlighted a number of improvements that could be made to LTV services, as well as areas of good care, which were often similar – Table 2.3 including: • Access to the wider multidisciplinary team - worked well 138/219 (63.0%) and could be improved 115/219 (52.5%) **CHAPTER 3 – PAGE 41/42** #11. Not all people had access to a physiotherapist in the community (34/40; 85% invasive, 49/82; 59.8% non-invasive) or to an occupational therapist (26/40; 65% invasive, 30/82; 36.6% non-invasive) – Table 3.5 #12. A medical lead for the LTV service was available in most LTV centres (<18 years of age 18/20; 90% vs ≥18 years of age 36/38; 94.7%) according to the organisational data – *Table 3.6* **CHAPTER 3 – PAGES 42/43** #13. The composition of the LTV teams in LTV centres varied; most included respiratory physiotherapy (<18 years of age 15/19; 78.9% vs ≥18 years of age 30/38; 78.9%) – *Table 3.7* #14. When people were admitted acutely some LTV services relied on the general physiotherapy rota to provide cover (<18 years of age 3/19; 15.8% vs ≥18 years of age 13/38; 34.2%) – *Table 3.7* #15. A minority of LTV services had speech and language therapy as part of their team (<18 years of age 7/20; 35% vs ≥18 years of age 14/39; 35.9%) and even fewer had psychology (<18 years of age 7/20; 35% vs ≥18 years of age 7/39; 17.9%) – Table 3.8	The Quality Review Service (formally West Midlands Quality Review Service) LTV Quality Standards: https://qualityreviewservicewm.nhs.uk/standards/page/2/

4	**Undertake shared decision-making at the point of long-term ventilation initiation, particularly if it is likely to be a life-long therapy.** The decision-making process should include input at all stages from: a) Children and young people (where ever possible) b) Parent carers c) The multidisciplinary team (MDT) listed in Recommendation 3 d) The person's general practitioner whenever practical/possible e) Palliative care when appropriate The process* should also include: f) Discussions over a period of time to ensure decisions are thoroughly considered g) Input from independent healthcare professionals for peer review/mediation as required h) Provision of approved written and/or online information i) Support from other families with a child on long-term ventilation should be considered *A nationally agreed decision-making and ethical framework for long-term ventilation care as proposed by Ray et al should be considered to aid the process. This should involve children young people and their families as key partners in any development *Ray S et al. 2018. Towards developing an ethical framework for decision-making in LTV in children. Archives of Disease in Childhood. 103(11): 1080–1084* ***Target audiences*** ***Children and Young People, Families, Service Planners/Commissioners and Trust/Health Board Executive Committees*** *with support from LTV Services, Social Care and Hospice/Respite Care, General Practice, Palliative Care, Medical and Surgical Royal Colleges, Clinical Networks, NHS England and the Departments of Health in the Welsh, Scottish and Northern Ireland Governments*	**CHAPTER 4 – PAGE 52** #47. Many clinicians referenced the potential benefit of forming an independent expert panel, to which people with complex needs, awaiting LTV could be referred to peer review/mediation. A multidisciplinary team of clinical experts, legal representatives, service planners and lay members was proposed to assist with difficult decision-making **CHAPTER 4 – PAGE 53** #45. For most people already established on ventilation (168/208; 80.8%), lead clinicians reported that LTV was started as 'destination' therapy i.e. with no immediate plan to discontinue – *Table 4.1* #46. Case reviewers and SAG members noted that there was a relative paucity of evidence on long-term outcomes from LTV to guide future decision-making #41. Where the primary intention was to perform a tracheostomy insertion for LTV (35/50; 70.0%), there was a clear record of how and when the decision was made for 23/35 (65.7%) people – *Table 4.2* **CHAPTER 4 – PAGE 59** #42. The implications of ongoing tracheostomy care at home had been discussed with 29/34 (85.3%) parent carers. It was reported that parent carers were given written/other media information to view prior to the decision being made to undertake tracheostomy insertion and commence LTV for just 9/50 (18.0%) people #43. Tracheostomies were performed as a scheduled procedure in 39/50 (78.0%) people with 11/50 (22.0%) reported as urgent or emergency procedures and 44/50 (88.0%) procedures were performed by ear, nose and throat surgeons. Importantly the operator was part of the multidisciplinary team that made the decision to commence LTV for 38/42 (90.5%) people (unknown in eight) #44. There were differences in opinion between clinicians and parent carers about whether a tracheostomy was appropriate for 5/31 (16.1%) people (unknown in 19)	NHSE Paediatric Critical Care and Surgery in Children Review https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup – register to access The Quality Review Service (formally West Midlands Quality Review Service) LTV Quality Standards: https://qualityreviewservicewm.nhs.uk/standards/page/2/ NHSE E07 – Service specification- Level 3 - Paediatric Critical Care (PCC) https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf

5	**Ensure that the planning for transition from child to adult services, including the provision of joint transition clinics, has clearly identifiable clinical and executive leadership and forms part of an integrated care pathway for people on long-term ventilation.** Developmentally appropriate and patient-centred transition planning should commence at the latest by the age of 14 years* **This supports NICE Guideline (NG43)* ***Target audiences*** ***Children and Young People, Families, LTV services and Trust/Health Board Executive Committees*** *with support from Clinical Directors, Healthcare Professionals in all hospitals (including those that are not LTV centres), Social Care, Primary Care and Service Planners/ Commissioners*	**CHAPTER 2 – PAGE 32** #6. Transition to adult services was also identified by parent carers and healthcare professionals as an area for improvement. Parent carers felt that little or no information or support was provided. Furthermore they reported that the professionals involved sometimes had a poor understanding of what the change meant in practice #7. Clinicians also noted that the arrangements for transition to adult services were not consistent. The pathway was often disjointed and the level of available support reduced as soon as transition took place **CHAPTER 3 – PAGE 46** #29. From the health and social care professionals' responses to the question on transition of care, 8/141 (5.7%) rated the services for transition to adult services as excellent (7 on the scale), and 73/141 (51.8%) rated them at 5-7, on the seven point scale used – Figure 3.4 **CHAPTER 3 – PAGES 47** #31. 71/74 (95.9%) people at the point of transition to adult services had a lead clinician for LTV care identified in adult health (this was unknown in 35 people), but a transition care plan, agreed in a multidisciplinary team meeting, occurred for only 28/91 (30.8%) people (18 unknown) **CHAPTER 3 – PAGES 47/48** #32. Review in a joint paediatric transition of care clinic was undertaken for 35/96 (36.5%) people (13 unknown) and where there had not been a review it was because there was no transition clinic available for 32/61 (52.5%) people #33. 5/32 (15.6%) community clinicians reported a need for clearer pathways for transition to adult services to be in place **CHAPTER 3 – PAGE 48** #34. Very few LTV centres involved the person's GP in transition of care planning (<18 years of age 7/18; 38.9% vs ≥18 years of age 8/29; 27.6%)	NICE Guideline 43: Transition https://www.nice.org.uk/guidance/ng43 NHSE Paediatric Critical Care and Surgery in Children Review https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup – register to access

6	**Provide a structured training programme and associated resources for long-term ventilation** which prepares: a) People on LTV and parent carers for home care b) Community providers for routine care c) Non-specialist clinicians for hospital admissions ***Target audiences*** ***Health Education England, NHS Education for Scotland, Health Education and Improvement Wales and Department of Health Northern Ireland*** *with support from, Children and Young People, Families, LTV Services, Medical Royal Colleges, Specialty Associations, Service Planners/Commissioners and Third Sector Organisations*	**CHAPTER 3 – PAGE 44** #23. Clinicians who led the admissions when there had been a new tracheostomy insertion for LTV stated that there had been delay at discharge due to non-clinical issues for 19/46 (41.3%) people, but unknown in four – *Table 3.12* **CHAPTER 4 – PAGE 56** #37. Training in preparation for common healthcare situations at home was reported to be received by 63/80 (78.8%) parent carers (not answered for nine), and 58/63 (92.1%) rated their confidence in dealing with urgent situations at 5-7, on the seven point scale used – *Figure 4.2* **CHAPTER 4 – PAGES 58** #38. There was a formal structured training programme to ensure community staff could manage LTV safely at home in 13/17 (76.5%) LTV centres in which <18 year olds were cared for, but only in 11/35 (31.4%) centres in which ≥18 year olds were cared for – *Table 4.6* #39. For parent carers, formal/structured training was provided in 16/21 (76.2%) LTV centres and competency assessments undertaken in 19/21 (90.5%) LTV centres in which people <18 years of age were cared for, compared with 11/39 (28.2%) and 18/39 (46.2%) LTV centres in which people ≥18 years were cared for **CHAPTER 6 – PAGE 75** #72. Health and social care professionals most commonly identified areas for improvement in relation to equipment services as training (98/233; 42.1%), competency (115/233; 49.4%), and out of hours support (107/233; 45.9%) – *Table 6.2* **CHAPTER 6 – PAGE 77** #75. In the community, 80/91 (87.9%) teams had received training in ventilator use, unknown for five teams. The community team was responsible for daily ventilator checks for only 27/91 (29.7%) people and there were 52/91 (57.1%) people where parent carers had specific responsibility	WellChild – Better at Home https://www.wellchild.org.uk/supporting-you/wellchild-better-home-suite/

7	**Standardise arrangements for long-term ventilation equipment** including: a) Purchasing b) Servicing c) Consumables ***Target audiences*** ***Service Planners/Commissioners and LTV Services***	**CHAPTER 2 – PAGE 33** #8. Clinician interviews highlighted variation between clinical commissioning groups such that individual hospitals could have differing arrangements for purchasing depending on the person's address **CHAPTER 6 – PAGE 73** #71. 72/85 (84.7%) people who were level 2 or 3 ventilator dependent had a backup ventilator available and 48/85 (56.5%) had a ventilator battery pack **CHAPTER 6 – PAGE 75** #72. Health and social care professionals most commonly identified areas for improvement in relation to equipment services as training (98/233; 42.1%), competency (115/233; 49.4%), and out of hours support (107/233; 45.9%) – *Table 6.2* #73. Equipment issues were also identified in the case notes of 20/149 (13.4%) people #74. 58/233 (24.9%) areas were highlighted by lead clinicians relating to standardisation of the ventilator and 68/233 (29.2%) areas related to community supply of disposables **CHAPTER 6 – PAGE 77** #75. In the community, 80/91 (87.9%) teams had received training in ventilator use, unknown for five teams. The community team was responsible for daily ventilator checks for only 27/91 (29.7%) people and there were 52/91 (57.1%) people where parent carers had specific responsibility #76. There was an equipment policy for LTV in the majority of hospitals (48/57; 84.2%), which generally specified what the arrangements were for ventilator servicing – *Table 6.4*	
8	**Standardise templates for personalised Emergency Healthcare Plans for all people on long-term ventilation.** They should: a) Be easily accessible by all members of the care team b) Be clearly laid out so that information can be easily recognised by all members of the care team c) Be reviewed at least annually, and after every hospital admission, by the clinical team and the service user/parent carer d) Form part of any hand-held records e) Include a fast-track admission plan ***Target audiences*** ***LTV Services*** *with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Service Users and Third Sector Organisations*	**CHAPTER 3 – PAGE 44** #16. In 42/50 (84.0%) people with a new tracheostomy a care package was available. In 40/42 (95.2%) of these people the care package in place clearly stated all of their needs, in the view of clinicians completing the tracheostomy insertion questionnaire. In 29/40 (72.5%) a 'tracheostomy passport' was included **CHAPTER 4 – PAGE 57** #35. Admitting clinicians reported that 63/135 (46.7%) of the people admitted during the two-year study period had a fast-track admission plan in place (unknown in 15), and of these 55/63 (87.3%) stated it had been followed – *Table 4.5* #36. 52/75 (69.3%) people in the sampled study population had an Emergency Healthcare Plan (EHP) in place, but a copy was only available in 23/149 (15.4%) sets of case notes	NHSE Paediatric Critical Care and Surgery in Children Review https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup – register to access

9	**Ensure all people on long-term ventilation have access to age appropriate emergency care** by a team with the relevant competencies, regardless of location. ***Target audiences*** ***Trust/Health Board Executive Committees*** *with support from LTV Services, Emergency Care, Ambulance Trusts, Critical Care Services and Healthcare Professionals in all hospitals (including those that are not LTV centres)*	**CHAPTER 5 – PAGE 62** #48. Most admissions (113/148; 76.4%) were unplanned, for urgent or emergency care. Planned admissions (35/148; 23.6%) were for surgery, respiratory review or respite care #49. People on LTV were most commonly admitted because they had increasing ventilator requirements (32/114; 28.1%) and/or problems with oxygenation (66/114; 57.9%) in the view of the case reviewers – Table 5.3 **CHAPTER 5 – PAGE 63** #50. On admission 36/139 (25.9%) people went straight to critical care. This did not always relate to critical illness and in many non-specialist hospitals, critical care was the only location where competences were appropriate to care for people on LTV **CHAPTER 5 – PAGE 65** #65. Clinicians who were interviewed stated that in their experience children requiring LTV were more likely to be admitted to a critical care environment **CHAPTER 5 – PAGE 66** #66. Location of admission was inappropriate for 13/149 (8.7%) people, in the opinion of the admitting clinicians #67. In 16/140 (11.4%) responses admitting clinicians stated that staffing was inappropriate for the person's needs due to the inadequate training and experience of both nursing and medical staff, in caring for people on LTV	
10	**Ensure good ventilation care when people on long-term ventilation are admitted to hospital for any reason by:** a) Undertaking a standard clinical and respiratory assessment b) Undertaking routine vital signs monitoring which includes, as a minimum, respiration rate and oxygen saturation c) Involving the usual LTV team if not admitted under their care d) Identifying clinical leadership of ventilation care ***Target audiences*** ***Healthcare Professionals in all hospitals (including those that are not LTV centres)*** *with support from Respiratory Clinicians, LTV Services and Critical Care Services*	**CHAPTER 5 – PAGE 66** #54. Case reviewers stated that 60/111 (54.1%) people had their usual team involved in multidisciplinary team discussions whilst as an inpatient, and evidence that members of the person's community team were involved in 25/75 (33.3%) cases reviewed – *Table 5.7* **CHAPTER 5 – PAGE 68** #55. Case reviewers stated that there was evidence of clinical leadership during the admission in the case notes of 82/137 (59.9%) people, but it could not be determined in 12 cases #56. Clinical leadership was more likely to be apparent if the admission was related directly to LTV care (41/62; 66.1% LTV admissions, 41/75; 54.7% non LTV admissions) – *Table 5.9* **CHAPTER 5 – PAGE 68/69** #60. Respiratory rate at admission was not documented in 18/135 (13.3%) sets of case notes – Table 5.10 #61. Oxygen saturation at admission was not documented in 13/133 (9.8%) sets of case notes – *Table 5.10* #62. Ventilator settings at admission were not documented in 38/148 (25.7%) sets of case notes – *Table 5.10* #63. Blood gas analysis was documented in 68/141 (48.2%) sets of case notes – *Table 5.11* #64. 64/141 (45.4%) people had a chest X-ray, of which 35 were admitted due to a primary respiratory cause – *Table 5.11*	NHSE Paediatric Critical Care and Surgery in Children Review https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup – register to access The Quality Review Service (formally West Midlands Quality Review Service) LTV Quality Standards: https://qualityreviewservicewm.nhs.uk/standards/page/2/

11	**Ensure high quality discharge arrangements for people established on long-term ventilation who are admitted to hospital.** Planning should: a) Commence on admission b) Be clearly documented in the case notes c) Include the community and usual LTV team d) Document any actual or anticipated changes to respiratory care ***Target audiences*** ***LTV Services with support from Healthcare Professionals in all hospitals (including those that are not LTV centres),*** *Primary Care and Social Care*	**CHAPTER 2 – PAGE 31** #5. Parent carers reported that the initial relief of receiving a diagnosis and specialist care was sometimes followed by frustration over the amount of time spent in hospital and delayed discharge **CHAPTER 3 – PAGE 44** #23. Clinicians who led the admissions when there had been a new tracheostomy insertion for LTV stated that there had been delay at discharge due to non-clinical issues for 19/46 (41.3%) people – *Table 3.12* #24. Case reviewers reported evidence of discharge planning in 64/126 (50.8%) sets of notes – *Table 3.13* **CHAPTER 3 – PAGE 45** #25. Evidence that the person's normal community team was involved in discharge planning was missing in 73/103 (70.9%) sets of notes and evidence that their usual lead LTV centre team was involved was missing in (68/113; 60.2%) sets of notes – *Table 3.14* #26. At discharge from the usual LTV centre, the admitting clinician reported changes in the long-term respiratory care for 24/83 (28.9%) people, and decisions made about long-term treatment goals for 13/78 (16.7%) people – *Table 3.15* #27. The admitting clinicians reported that a discharge summary was provided for 138/146 (94.5%) people (unknown in five) and a revised care plan was provided at discharge for 43/124 (34.7%) people – *Table 3.16*	The Regulation and Quality Improvement Authority. Audit of discharge of children on long-term ventilation https://www.rqia.org.uk/RQIA/files/a8/a871fa4d-6cda-41cb-8073-4ce93ffb285a.pdf
12	**Optimise the frequency of clinical review on an individual basis, for those on long-term ventilation who are at an increased risk of admission*** **including people established on LTV < 2 years and those who have had an unplanned admission in the previous 6 months* ***Target audiences*** ***LTV Services*** *with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Primary Care and Social Care*	**CHAPTER 5 – PAGE 62** #51. At the time of admission, and where it could be answered, 86/135 (63.7%) people had been receiving LTV for ≥2 years with a range of 2 -23 years **CHAPTER 5 – PAGE 67** #53. Senior clinical review within 14 hours of admission was documented for 54/77 (70.1%) people who were admitted as an emergency – *Table 5.8* **CHAPTER 5 – PAGE 68** #55. Case reviewers stated that there was evidence of clinical leadership during the admission in the case notes of 82/137 (59.9%) people, but it could not be determined in 12 cases #56. Clinical leadership was more likely to be apparent if the admission was related directly to LTV care (41/62; 66.1% LTV admissions, 41/75; 54.7% non LTV admissions) – *Table 5.9* **CHAPTER 5 – PAGE 70** #57. An acute admission to the same hospital, in the previous six-months, had occurred in 68/145 (46.9%) people in the study, unknown in seven. The majority of these (56/68; 82.4%) were unplanned and in 46/68 (67.6%) people it was for an acute illness – Table 5.12 #58. People who had been on LTV for <2 years were more likely to have had an unplanned admission in the previous six-months when compared to those receiving LTV for ≥2 years – *Table 5.13*	

Appendix 2 – Shared learning ideas arising from the data

- Clinicians reported that the appointment of key professionals, such as a nurse co-ordinator, to facilitate communication between specialist and non-specialist hospital teams, and the service user, their community teams and parent carers improved commissioning of LTV services. *Ch. 3*

- Some LTV services had developed the role of a dedicated professional to manage a fluid pathway for the transition to adult services. *Ch. 3*

- A nurse consultant reported that they had appointed a Paediatric LTV Nurse to lead on transition to adult service. They also suggested that there is a lot to learn from the severe asthma model of care. *Ch. 3*

- General practitioners may well find themselves with a key role in clinical care of LTV, particularly at or after transition to adult services so not being involved is a missed opportunity. GP reviewers in this study suggested that e-communication may be the most efficient method of communication. *Ch. 3*

- To improve communication, service users and parent carers stated that there was a need to provide more opportunities for them to ask questions. *Ch. 4*

- There were several comments made during the clinician interviews relating to the challenges of dealing with conflicting views between clinicians and parent carers. Many referenced the potential benefit of forming an independent expert panel, to which people with complex needs, awaiting LTV could be referred for peer review/mediation. A multidisciplinary team of clinical experts, legal representatives, service planners and lay members was proposed to assist with difficult decision-making. Clinicians also stated that this might potentially prevent prolonged medico-legal cases and assist the person on LTV, their family and clinicians. *Ch. 4*

- Where differences in opinion between clinicians and parent carers about whether a tracheostomy was appropriate occurred, it led to various methods of resolution, including formal/informal multidisciplinary discussions, seeking a second opinion within the same hospital and involvement of an ethics committee. *Ch. 4*

- One clinician reported that in their organisation, the ambulance Trust and hospital Trust had access to shared notes and documentations. When a 999 call went out to the home of a child on LTV, the paramedics could alert the hospital to their arrival. This ensured the child was reviewed as soon as they reached the emergency department and even fast-tracked to critical care if needed. *Ch. 4*

- Clinicians identified the importance of providing clinical and technical support for people on LTV and their families. Models of service reported to work well included the provision of outreach services by the hospital team or WellChild nurses. *Ch. 6*

- A model of care that included access to home sleep studies was an area of practice that parent carers highlighted as being important to them. *Ch. 6*

Appendix 3 – Participation

Trust/Health Board	Case identification spreadsheet returned, people subsequently identified, or notified of no cases for inclusion	Clinical questionnaire data returned	Case notes returned	Organisational questionnaire returned
Aintree Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Airedale NHS Foundation Trust	Yes	-	-	-
Alder Hey Children's NHS Foundation Trust	Yes	Yes	Yes	Yes
Aneurin Bevan University Health Board	Yes	-	-	-
Ashford & St Peter's Hospitals NHS Trust	Yes	Yes	Yes	Yes
Barking, Havering & Redbridge University Hospitals NHS Trust	Yes	-	-	-
Barnsley Hospital NHS Foundation Trust	No	-	-	-
Barts Health NHS Trust	Yes	No	No	No
Basildon & Thurrock University Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Bedford Hospital NHS Trust	Yes	-	-	-
Belfast Health and Social Care Trust	Yes	No	No	No
Berkshire Healthcare NHS Foundation Trust	Yes	Yes	-	-
Betsi Cadwaladr University Local Health Board	Yes	-	-	No
Birmingham Community Healthcare NHS Trust	Yes	Yes	-	Yes
Birmingham Women's and Children's NHS Foundation Trust	Yes	Yes	Yes	No
Blackpool Teaching Hospitals NHS Foundation Trust	Yes	No	Yes	Yes
Bolton Hospital NHS Foundation Trust	Yes	-	-	-
Bradford Teaching Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Bridgewater Community Healthcare NHS Foundation Trust	Yes	Yes	-	Yes
Brighton and Sussex University Hospitals NHS Trust	Yes	Yes	Yes	Yes
Buckinghamshire Healthcare NHS Trust	Yes	Yes	Yes	Yes
Calderdale & Huddersfield NHS Foundation Trust	Yes	-	-	-
Cambridge University Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Cardiff and Vale University Health Board	Yes	Yes	Yes	Yes
Central and North West London NHS Foundation Trust	Yes	Yes	-	Yes
Chelsea & Westminster NHS Foundation Trust	Yes	-	-	-
Cornwall Partnership NHS Foundation Trust	Yes	Yes	-	Yes
Countess of Chester Hospital NHS Foundation Trust	Yes	Yes	Yes	Yes
County Durham and Darlington NHS Foundation Trust	Yes	-	-	Yes
Coventry & Warwickshire Partnership NHS Trust	Yes	Yes	-	Yes
Croydon Health Services NHS Trust	Yes	Yes	-	Yes
Cwm Taf University Health Board	Yes	Yes	Yes	Yes
Dartford & Gravesham NHS Trust	Yes	-	-	-
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Yes	-	-	-
Dorset County Hospital NHS Foundation Trust	Yes	Yes	Yes	Yes

Trust/Health Board	Case identification spreadsheet returned, people subsequently identified, or notified of no cases for inclusion	Clinical questionnaire data returned	Case notes returned	Organisational questionnaire returned
East & North Hertfordshire NHS Trust	Yes	-	-	Yes
East Cheshire NHS Trust	Yes	-	-	-
East Kent Hospitals University NHS Foundation Trust	Yes	No	No	No
East Lancashire Hospitals NHS Trust	Yes	Yes	Yes	Yes
East Suffolk and North Essex NHS Foundation Trust (ESNEFT)	Yes	Yes	Yes	Yes
East Sussex Healthcare NHS Trust	Yes	-	-	-
Epsom and St Helier University Hospitals NHS Trust	Yes	Yes	No	Yes
Frimley Health NHS Foundation Trust	Yes	Yes	Yes	Yes
Gateshead Health NHS Foundation Trust	Yes	-	-	-
George Eliot Hospital NHS Trust	Yes	-	-	-
Gloucestershire Care Services NHS Trust	Yes	Yes	-	Yes
Gloucestershire Hospitals NHS Foundation Trust	Yes	Yes	No	Yes
Great Ormond Street Hospital for Children NHS Trust	Yes	Yes	Yes	Yes
Great Western Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Guy's & St Thomas' NHS Foundation Trust	Yes	Yes	Yes	Yes
Hampshire Hospitals NHS Foundation Trust	Yes	-	-	-
Harrogate and District NHS Foundation Trust	Yes	-	-	-
HCA International	Yes	-	-	-
Hillingdon Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Homerton University Hospital NHS Foundation Trust	Yes	-	-	Yes
Hounslow and Richmond Community Healthcare NHS Trust	Yes	Yes	-	Yes
Hull University Teaching Hospitals NHS Trust	Yes	-	-	Yes
Hywel Dda University Health Board	Yes	-	-	-
Imperial College Healthcare NHS Trust	Yes	Yes	Yes	Yes
Isle of Man Department of Health & Social Security	Yes	No	-	Yes
Isle of Wight NHS Trust	Yes	-	-	-
James Paget University Hospitals NHS Foundation Trust	Yes	-	-	-
Kent Community Health NHS Foundation Trust	Yes	-	-	Yes
Kettering General Hospital NHS Foundation Trust	Yes	-	-	Yes
King's College Hospital NHS Foundation Trust	Yes	Yes	Yes	Yes
Kingston Hospital NHS Foundation Trust	Yes	Yes	Yes	Yes
Lancashire Care NHS Foundation Trust	Yes	-	-	Yes
Lancashire Teaching Hospitals NHS Foundation Trust	Yes	No	Yes	No
Leeds Community Healthcare NHS Trust	Yes	-	-	No
Leicestershire Partnership NHS Trust	Yes	Yes	-	No
Lewisham and Greenwich NHS Trust	No	-	-	-
London North West University Healthcare NHS Trust	Yes	-	-	Yes
Luton and Dunstable Hospital NHS Foundation Trust	No	-	-	-
Maidstone and Tunbridge Wells NHS Trust	Yes	-	-	-
Manchester University NHS Foundation Trust	Yes	Yes	Yes	Yes

Trust/Health Board	Case identification spreadsheet returned, people subsequently identified, or notified of no cases for inclusion	Clinical questionnaire data returned	Case notes returned	Organisational questionnaire returned
Mid Essex Hospitals NHS Trust	Yes	-	-	-
Mid Yorkshire Hospitals NHS Trust	Yes	Yes	Yes	No
Midlands Partnership NHS Foundation Trust	Yes	Yes	-	Yes
Milton Keynes University Hospital NHS Foundation Trust	Yes	-	-	-
Newcastle upon Tyne Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
NHS Borders	No	-	-	-
NHS Dumfries & Galloway	No	-	-	-
NHS Fife	No	-	-	-
NHS Forth Valley	No	-	-	-
NHS Grampian	Yes	Yes	Yes	No
NHS Greater Glasgow & Clyde	No	-	-	-
NHS Lothian	No	-	-	-
NHS Tayside	No	-	-	-
Norfolk & Norwich University Hospital NHS Trust	Yes	Yes	No	Yes
Norfolk Community Health & Care NHS Trust	Yes	Yes	-	Yes
North Cumbria University Hospitals NHS Trust	Yes	-	-	-
North Middlesex University Hospital NHS Trust	Yes	-	-	-
North Tees and Hartlepool NHS Foundation Trust	Yes	-	-	-
North West Anglia NHS Foundation Trust	Yes	Yes	Yes	Yes
Northampton General Hospital NHS Trust	Yes	Yes	Yes	Yes
Northern Devon Healthcare NHS Trust	Yes	Yes	Yes	Yes
Northern Health & Social Care Trust	No	-	-	-
Northern Lincolnshire & Goole NHS Foundation Trust	Yes	Yes	Yes	Yes
Northumbria Healthcare NHS Foundation Trust	Yes	-	-	-
Nottingham University Hospitals NHS Trust	Yes	Yes	Yes	Yes
Oxford Health NHS Foundation Trust	Yes	Yes	-	Yes
Oxford University Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Oxleas NHS Foundation Trust	No	-	-	Yes
Papworth Hospital NHS Foundation Trust	No	-	-	-
Pennine Acute Hospitals NHS Trust	No	-	-	-
Pennine Care NHS Foundation Trust	Yes	-	-	Yes
Poole Hospital NHS Foundation Trust	No	-	-	-
Portsmouth Hospitals NHS Trust	Yes	Yes	Yes	Yes
Powys Teaching Local Health Board	Yes	-	-	-
Rotherham NHS Foundation Trust	Yes	-	-	-
Royal Berkshire NHS Foundation Trust	Yes	Yes	Yes	Yes
Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Yes	-	-	-
Royal Brompton and Harefield NHS Foundation Trust	Yes	Yes	No	Yes
Royal Cornwall Hospitals NHS Trust	Yes	No	Yes	Yes
Royal Devon and Exeter NHS Foundation Trust	Yes	-	-	-

Trust/Health Board	Case identification spreadsheet returned, people subsequently identified, or notified of no cases for inclusion	Clinical questionnaire data returned	Case notes returned	Organisational questionnaire returned
Royal Free London NHS Foundation Trust	Yes	-	-	-
Royal Liverpool & Broadgreen University Hospitals NHS Trust	Yes	-	-	-
Royal National Orthopaedic Hospital NHS Trust	Yes	-	-	-
Royal Surrey County Hospital NHS Foundation Trust	Yes	-	-	-
Royal United Hospitals Bath NHS Foundation Trust	Yes	-	-	-
Salford Royal Hospitals NHS Foundation Trust	Yes	Yes	-	Yes
Salisbury NHS Foundation Trust	Yes	Yes	Yes	Yes
Sandwell and West Birmingham Hospitals NHS Trust	Yes	Yes	Yes	Yes
Sheffield Children's NHS Foundation Trust	Yes	Yes	Yes	No
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Sherwood Forest Hospitals NHS Foundation Trust	Yes	-	-	-
Shrewsbury and Telford Hospitals NHS Trust	No	-	-	-
Solent NHS Trust	Yes	Yes	-	Yes
South Eastern Health & Social Care Trust	Yes	No	Yes	No
South Tees Hospitals NHS Foundation Trust	Yes	-	-	Yes
South Tyneside and Sunderland NHS Foundation Trust	Yes	Yes	Yes	Yes
South Warwickshire NHS Foundation Trust	Yes	Yes	No	No
Southend University Hospital NHS Foundation Trust	Yes	-	-	-
Southern Health & Social Care Trust	Yes	Yes	Yes	Yes
Southport & Ormskirk Hospitals NHS Trust	Yes	Yes	No	Yes
St George's University Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
St Helens and Knowsley Teaching Hospitals NHS Trust	Yes	-	-	-
States of Jersey Health & Social Services	Yes	-	-	-
Stockport NHS Foundation Trust	Yes	-	-	No
Surrey and Sussex Healthcare NHS Trust	Yes	No	No	No
Sussex Community NHS Foundation Trust	Yes	Yes	-	Yes
Swansea Bay University Local Health Board	Yes	-	-	Yes
Taunton & Somerset NHS Foundation Trust	Yes	Yes	Yes	Yes
The Dudley Group NHS Foundation Trust	No	-	-	-
The Leeds Teaching Hospitals NHS Trust	Yes	Yes	Yes	Yes
The Princess Alexandra Hospital NHS Trust	Yes	-	-	-
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Yes	-	-	Yes
The Royal Marsden NHS Foundation Trust	Yes	-	-	-
The Royal Wolverhampton Hospitals NHS Trust	Yes	-	-	-
The University Hospitals of the North Midlands NHS Trust	Yes	Yes	Yes	Yes
Torbay and South Devon NHS Foundation Trust	Yes	Yes	Yes	Yes
United Lincolnshire Hospitals NHS Trust	Yes	Yes	-	Yes
University College London Hospitals NHS Foundation Trust	Yes	Yes	-	Yes

Trust/Health Board	Case identification spreadsheet returned, people subsequently identified, or notified of no cases for inclusion	Clinical questionnaire data returned	Case notes returned	Organisational questionnaire returned
University Hospital Southampton NHS Foundation Trust	Yes	Yes	Yes	Yes
University Hospitals Birmingham NHS Foundation Trust	Yes	Yes	Yes	Yes
University Hospitals Coventry and Warwickshire NHS Trust	Yes	Yes	Yes	Yes
University Hospitals of Bristol NHS Foundation Trust	Yes	No	No	Yes
University Hospitals of Derby and Burton NHS Foundation Trust	Yes	Yes	Yes	Yes
University Hospitals of Leicester NHS Trust	Yes	Yes	Yes	Yes
University Hospitals of Morecambe Bay NHS Trust	Yes	-	-	Yes
University Hospitals Plymouth NHS Trust	Yes	Yes	No	Yes
Walsall Healthcare NHS Trust	Yes	-	-	-
Warrington & Halton Hospitals NHS Foundation Trust	Yes	-	-	-
West Hertfordshire Hospitals NHS Trust	Yes	-	-	-
West Suffolk NHS Foundation Trust	No	-	-	-
Western Health & Social Care Trust	No	-	-	-
Western Sussex Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Weston Area Health Trust	No	-	-	-
Whittington Health NHS Trust	Yes	-	-	Yes
Wirral University Teaching Hospital NHS Foundation Trust	No	-	-	-
Worcestershire Acute Hospitals NHS Trust	Yes	-	-	-
Wrightington, Wigan & Leigh NHS Foundation Trust	Yes	Yes	Yes	Yes
Wye Valley NHS Trust	Yes	-	-	-
Yeovil District Hospital NHS Foundation Trust	Yes	-	-	-
York Teaching Hospital NHS Foundation Trust	Yes	-	-	-

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