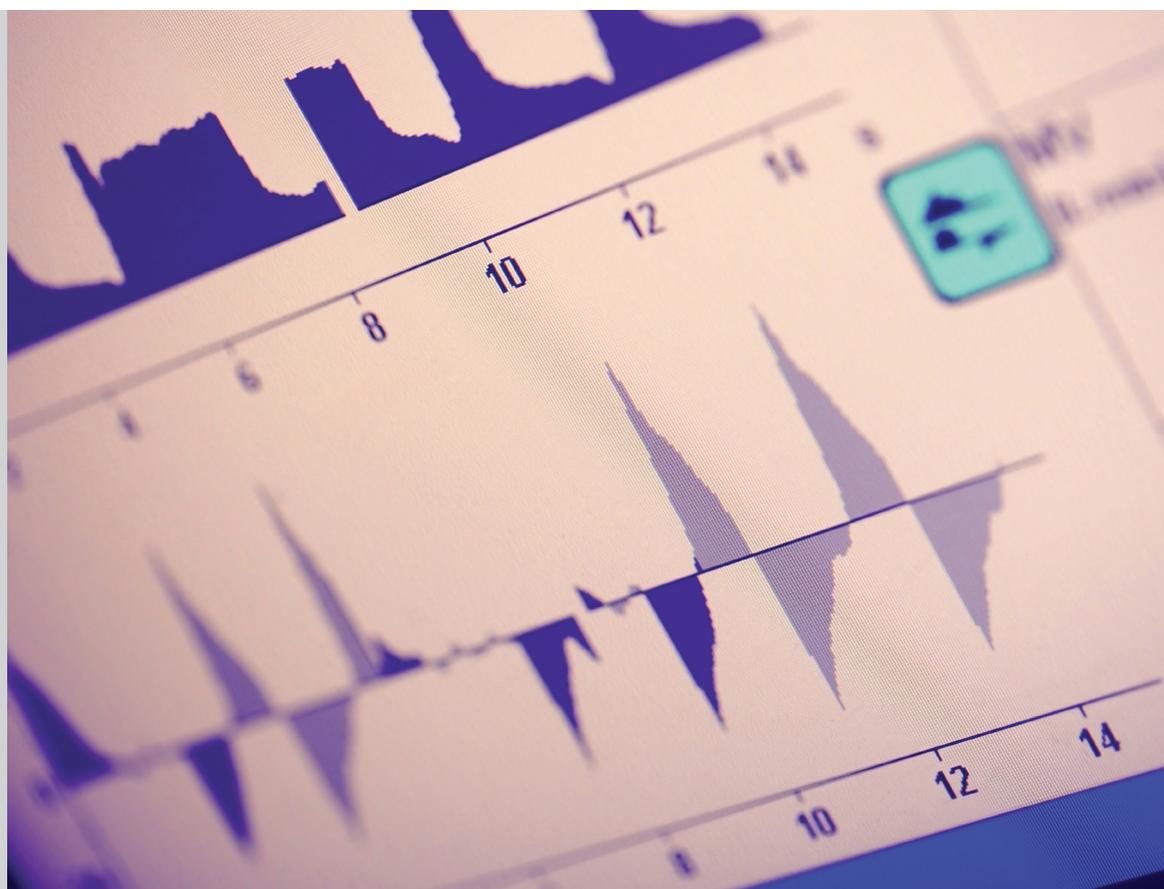


# Balancing the Pressures

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

summary



# 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

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

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# Introduction

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## 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.<sup>2</sup> 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.<sup>3</sup> 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.<sup>4,5</sup>

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.<sup>6</sup> 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)*"<sup>16</sup> 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.<sup>3</sup> 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.<sup>7-9</sup>

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.<sup>10</sup> 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.<sup>11</sup>

However, it is not all negative. An ethical framework which supports the decision-making process for LTV has been proposed.<sup>12</sup> 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.

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# Executive summary

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## 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

## Line of sight between the recommendations, key findings and existing supporting evidence

| <p>Suggested target audiences to action the recommendations are listed in italics under each one. The primary target audience/audiences are in bold.</p> <p><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></p>   | <p># is the number of the supporting key data in the report</p>   | <p>Associated guidelines and other related evidence</p>   |
|--|---|---|
| <p>1</p> <p><b>Ensure service planning/commissioning of integrated care pathways for long-term ventilation services includes formal contract arrangements and local standardisation where possible.</b></p> <p>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.</p> <p><b>Target audiences</b><br/> <b>Service Planners/Commissioners (National and Local)</b> with support from <i>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></p> | <p><b>CHAPTER 2 – PAGE 29</b></p> <p>#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:</p> <ul style="list-style-type: none"> <li>• Access to the wider multidisciplinary team - worked well 138/219 (63.0%) and could be improved 115/219 (52.5%)</li> <li>• Access to services - worked well 35/219 (16.0%) and could be improved 70/219 (32.0%)</li> <li>• Improved clinical knowledge and skills about LTV - worked well 26/219 (11.9%) and could be improved 48/219 (21.9%)</li> <li>• Respite/hospice care - worked well 21/219 (9.6%) and could be improved 15/219 (6.8%)</li> </ul> <p><b>CHAPTER 3 – PAGE 37</b></p> <p>#18. Commissioning of LTV services was rated 5-7 on a seven point scale by 68/167 (40.7%) health and social care professionals – <i>Figure 3.2</i></p> <p><b>CHAPTER 3 – PAGE 38/39</b></p> <p>#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 – <i>Table 3.2</i></p> <p>#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 &lt;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%) – <i>Table 3.3</i></p> <p><b>CHAPTER 3 – PAGE 39</b></p> <p>#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 – <i>Figure 3.3</i></p> | <p>The Quality Review Service (formerly West Midlands Quality Review Service) LTV Quality Standards: <a href="https://qualityreviewservicewm.nhs.uk/standards/page/2/">https://qualityreviewservicewm.nhs.uk/standards/page/2/</a></p> <p>NHSE E07 – Service specification- Level 3 - Paediatric Critical Care (PCC) <a href="https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf">https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf</a></p> <p>NHSE Paediatric Critical Care and Surgery in Children Review <a href="https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2Fpaedreview%2FjoinGroup">https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2Fpaedreview%2FjoinGroup</a> – register to access</p> |

## RECOMMENDATIONS

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| <p>2</p> | <p><b>Ensure that it is possible to identify all people who are receiving long-term ventilation.</b></p> <p>a) Locally this should be achieved by implementing/maintaining a database as soon as possible</p> <p>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</p> <p><b>Target audiences</b><br/> <b>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</b></p>   | <p><b>CHAPTER 1 – PAGE 16</b><br/> #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</p> <p><b>CHAPTER 1 – PAGE 19</b><br/> #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</p> <p><b>CHAPTER 3 – PAGE 37</b><br/> #10. An annual audit of people on LTV was undertaken in 32/63 (50.8%) LTV centres – <i>Table 3.1</i></p>  | <p>NHSE Paediatric Critical Care and Surgery in Children Review<br/> <a href="https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup">https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup</a> – register to access</p> |
| <p>3</p> | <p><b>Ensure efficient care planning and discharge by providing a multidisciplinary team as part of an integrated care pathway.</b> 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:</p> <p>a) Medical and nursing staff<br/> b) Physiotherapy<br/> c) Speech and language therapy<br/> d) Psychology<br/> Where applicable<br/> e) A specialist in tracheostomy care<br/> f) Palliative care/hospice care<br/> g) Local service planners/commissioners</p> <p><b>Target audiences</b><br/> <b>Service Planners/Commissioners and Trust/Health Board Executive Committees with support from LTV Services, Social Care and Hospice/Respite Care, Psychology and Palliative Care</b></p> | <p><b>CHAPTER 2 – PAGE 29</b><br/> #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 – <i>Table 2.3</i> including:</p> <ul style="list-style-type: none"> <li>• Access to the wider multidisciplinary team - worked well 138/219 (63.0%) and could be improved 115/219 (52.5%)</li> </ul> <p><b>CHAPTER 3 – PAGE 41/42</b><br/> #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) – <i>Table 3.5</i></p> <p>#12. A medical lead for the LTV service was available in most LTV centres (&lt;18 years of age 18/20; 90% vs ≥18 years of age 36/38; 94.7%) according to the organisational data – <i>Table 3.6</i></p> <p><b>CHAPTER 3 – PAGES 42/43</b><br/> #13. The composition of the LTV teams in LTV centres varied; most included respiratory physiotherapy (&lt;18 years of age 15/19; 78.9% vs ≥18 years of age 30/38; 78.9%) – <i>Table 3.7</i></p> <p>#14. When people were admitted acutely some LTV services relied on the general physiotherapy rota to provide cover (&lt;18 years of age 3/19; 15.8% vs ≥18 years of age 13/38; 34.2%) – <i>Table 3.7</i></p> <p>#15. A minority of LTV services had speech and language therapy as part of their team (&lt;18 years of age 7/20; 35% vs ≥18 years of age 14/39; 35.9%) and even fewer had psychology (&lt;18 years of age 7/20; 35% vs ≥18 years of age 7/39; 17.9%) – <i>Table 3.8</i></p> | <p>The Quality Review Service (formerly West Midlands Quality Review Service) LTV Quality Standards: <a href="https://qualityreviewservicewm.nhs.uk/standards/page/2/">https://qualityreviewservicewm.nhs.uk/standards/page/2/</a></p>  |

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| <p>4</p> | <p><b>Undertake shared decision-making at the point of long-term ventilation initiation, particularly if it is likely to be a life-long therapy.</b> The decision-making process should include input at all stages from:</p> <ul style="list-style-type: none"> <li>a) Children and young people (where ever possible)</li> <li>b) Parent carers</li> <li>c) The multidisciplinary team (MDT) listed in Recommendation 3</li> <li>d) The person’s general practitioner whenever practical/possible</li> <li>e) Palliative care when appropriate</li> </ul> <p>The process* should also include:</p> <ul style="list-style-type: none"> <li>f) Discussions over a period of time to ensure decisions are thoroughly considered</li> <li>g) Input from independent healthcare professionals for peer review/mediation as required</li> <li>h) Provision of approved written and/or online information</li> <li>i) Support from other families with a child on long-term ventilation should be considered</li> </ul> <p>*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</p> <p><i>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</i></p> <p><b>Target audiences</b><br/> <b>Children and Young People, Families, Service Planners/Commissioners and Trust/Health Board Executive Committees</b><br/> <i>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</i></p> | <p><b>CHAPTER 4 – PAGE 52</b><br/> #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</p> <p><b>CHAPTER 4 – PAGE 53</b><br/> #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 – <i>Table 4.1</i></p> <p>#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 – <i>Table 4.2</i></p> <p><b>CHAPTER 4 – PAGE 59</b><br/> #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</p> <p>#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)</p> <p>#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)</p> | <p>NHSE Paediatric Critical Care and Surgery in Children Review<br/> <a href="https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup">https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup</a> – register to access</p> <p>The Quality Review Service (formerly West Midlands Quality Review Service) LTV Quality Standards: <a href="https://qualityreview servicewm.nhs.uk/standards/page/2/">https://qualityreview servicewm.nhs.uk/standards/page/2/</a></p> <p>NHSE E07 – Service specification- Level 3 - Paediatric Critical Care (PCC)<br/> <a href="https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf">https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf</a></p> |
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## RECOMMENDATIONS

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| <p>5</p> | <p><b>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.</b> Developmentally appropriate and patient-centred transition planning should commence at the latest by the age of 14 years*<br/>*This supports NICE Guideline (NG43)</p> <p><b>Target audiences</b><br/><b>Children and Young People, Families, LTV services and Trust/Health Board Executive Committees</b> with support from <i>Clinical Directors, Healthcare Professionals in all hospitals (including those that are not LTV centres), Social Care, Primary Care and Service Planners/Commissioners</i></p> | <p><b>CHAPTER 2 – PAGE 32</b><br/>#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<br/>#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<br/><b>CHAPTER 3 – PAGE 46</b><br/>#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<br/><b>CHAPTER 3 – PAGES 47</b><br/>#31. 71/74 (95.9%) people 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)<br/><b>CHAPTER 3 – PAGES 47/48</b><br/>#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<br/>#33. 5/32 (15.6%) community clinicians reported a need for clearer pathways for transition to adult services to be in place<br/><b>CHAPTER 3 – PAGE 48</b><br/>#34. Very few LTV centres involved the person's GP in transition of care planning (&lt;18 years of age 7/18; 38.9% vs ≥18 years of age 8/29; 27.6%)</p> | <p>NICE Guideline 43: Transition<br/><a href="https://www.nice.org.uk/guidance/ng43">https://www.nice.org.uk/guidance/ng43</a></p> <p>NHSE Paediatric Critical Care and Surgery in Children Review<br/><a href="https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2Fpaedreview%2FjoinGroup">https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2Fpaedreview%2FjoinGroup</a> – register to access</p> |
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RECOMMENDATIONS

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| <p>6</p> | <p><b>Provide a structured training programme and associated resources for long-term ventilation</b> which prepares:</p> <ul style="list-style-type: none"> <li>a) People on LTV and parent carers for home care</li> <li>b) Community providers for routine care</li> <li>c) Non-specialist clinicians for hospital admissions</li> </ul> <p><b>Target audiences</b><br/> <b>Health Education England, NHS Education for Scotland, Health Education and Improvement Wales and Department of Health Northern Ireland</b> with support from, <i>Children and Young People, Families, LTV Services, Medical Royal Colleges, Specialty Associations, Service Planners/Commissioners and Third Sector Organisations</i></p> | <p><b>CHAPTER 3 – PAGE 44</b><br/>         #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 – <i>Table 3.12</i></p> <p><b>CHAPTER 4 – PAGE 56</b><br/>         #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 – <i>Figure 4.2</i></p> <p><b>CHAPTER 4 – PAGES 58</b><br/>         #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 &lt;18 year olds were cared for, but only in 11/35 (31.4%) centres in which ≥18 year olds were cared for – <i>Table 4.6</i></p> <p>#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 &lt;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</p> <p><b>CHAPTER 6 – PAGE 75</b><br/>         #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%) – <i>Table 6.2</i></p> <p><b>CHAPTER 6 – PAGE 77</b><br/>         #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</p> | <p>WellChild – Better at Home<br/> <a href="https://www.wellchild.org.uk/supporting-you/wellchild-better-home-suite/">https://www.wellchild.org.uk/supporting-you/wellchild-better-home-suite/</a></p> |
|----------|---|--|--|

## RECOMMENDATIONS

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|---|---|--|--|
| 7 | <p><b>Standardise arrangements for long-term ventilation equipment</b> including:</p> <ul style="list-style-type: none"> <li>a) Purchasing</li> <li>b) Servicing</li> <li>c) Consumables</li> </ul> <p><b>Target audiences</b><br/><b>Service Planners/Commissioners and LTV Services</b></p>   | <p><b>CHAPTER 2 – PAGE 33</b><br/>#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</p> <p><b>CHAPTER 6 – PAGE 73</b><br/>#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</p> <p><b>CHAPTER 6 – PAGE 75</b><br/>#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%) – <i>Table 6.2</i></p> <p>#73. Equipment issues were also identified in the case notes of 20/149 (13.4%) people</p> <p>#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</p> <p><b>CHAPTER 6 – PAGE 77</b><br/>#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</p> <p>#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 – <i>Table 6.4</i></p> |  |
| 8 | <p><b>Standardise templates for personalised Emergency Healthcare Plans for all people on long-term ventilation.</b> They should:</p> <ul style="list-style-type: none"> <li>a) Be easily accessible by all members of the care team</li> <li>b) Be clearly laid out so that information can be easily recognised by all members of the care team</li> <li>c) Be reviewed at least annually, and after every hospital admission, by the clinical team and the service user/parent carer</li> <li>d) Form part of any hand-held records</li> <li>e) Include a fast-track admission plan</li> </ul> <p><b>Target audiences</b><br/><b>LTV Services with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Service Users and Third Sector Organisations</b></p> | <p><b>CHAPTER 3 – PAGE 44</b><br/>#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</p> <p><b>CHAPTER 4 – PAGE 57</b><br/>#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 – <i>Table 4.5</i></p> <p>#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</p>  | <p>NHSE Paediatric Critical Care and Surgery in Children Review<br/><a href="https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup">https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup</a> – register to access</p> |

## RECOMMENDATIONS

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|----|---|---|--|
| 9  | <p><b>Ensure all people on long-term ventilation have access to age appropriate emergency care</b> by a team with the relevant competencies, regardless of location.</p> <p><b>Target audiences</b><br/> <b>Trust/Health Board Executive Committees</b><br/> <i>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)</i></p>   | <p><b>CHAPTER 5 – PAGE 62</b><br/> #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<br/> #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<br/> <b>CHAPTER 5 – PAGE 63</b><br/> #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<br/> <b>CHAPTER 5 – PAGE 65</b><br/> #65. Clinicians who were interviewed stated that in their experience children requiring LTV were more likely to be admitted to a critical care environment<br/> <b>CHAPTER 5 – PAGE 66</b><br/> #66. Location of admission was inappropriate for 13/149 (8.7%) people, in the opinion of the admitting clinicians<br/> #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</p> |  |
| 10 | <p><b>Ensure good ventilation care when people on long-term ventilation are admitted to hospital for any reason by:</b></p> <ol style="list-style-type: none"> <li>Undertaking a standard clinical and respiratory assessment</li> <li>Undertaking routine vital signs monitoring which includes, as a minimum, respiration rate and oxygen saturation</li> <li>Involving the usual LTV team if not admitted under their care</li> <li>Identifying clinical leadership of ventilation care</li> </ol> <p><b>Target audiences</b><br/> <b>Healthcare Professionals in all hospitals (including those that are not LTV centres)</b><br/> <i>with support from Respiratory Clinicians, LTV Services and Critical Care Services</i></p> | <p><b>CHAPTER 5 – PAGE 66</b><br/> #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<br/> <b>CHAPTER 5 – PAGE 68</b><br/> #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<br/> #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<br/> <b>CHAPTER 5 – PAGE 68/69</b><br/> #60. Respiratory rate at admission was not documented in 18/135 (13.3%) sets of case notes – Table 5.10<br/> #61. Oxygen saturation at admission was not documented in 13/133 (9.8%) sets of case notes – Table 5.10<br/> #62. Ventilator settings at admission were not documented in 38/148 (25.7%) sets of case notes – Table 5.10<br/> #63. Blood gas analysis was documented in 68/141 (48.2%) sets of case notes – Table 5.11<br/> #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</p> | <p>NHSE Paediatric Critical Care and Surgery in Children Review<br/> <a href="https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2Fpaedreview%2FjoinGroup">https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2Fpaedreview%2FjoinGroup</a> – register to access</p> <p>The Quality Review Service (formerly West Midlands Quality Review Service) LTV Quality Standards: <a href="https://qualityreview servicewm.nhs.uk/standards/page/2/">https://qualityreview servicewm.nhs.uk/standards/page/2/</a></p> |

## RECOMMENDATIONS

|    |   |   |   |
|----|---|---|---|
| 11 | <p><b>Ensure high quality discharge arrangements for people established on long-term ventilation who are admitted to hospital.</b> Planning should:</p> <ol style="list-style-type: none"> <li>Commence on admission</li> <li>Be clearly documented in the case notes</li> <li>Include the community and usual LTV team</li> <li>Document any actual or anticipated changes to respiratory care</li> </ol> <p><b>Target audiences</b><br/> <b>LTV Services with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Primary Care and Social Care</b></p> | <p><b>CHAPTER 2 – PAGE 31</b><br/> #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</p> <p><b>CHAPTER 3 – PAGE 44</b><br/> #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 – <i>Table 3.12</i><br/> #24. Case reviewers reported evidence of discharge planning in 64/126 (50.8%) sets of notes – <i>Table 3.13</i></p> <p><b>CHAPTER 3 – PAGE 45</b><br/> #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 – <i>Table 3.14</i><br/> #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 – <i>Table 3.15</i><br/> #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 – <i>Table 3.16</i></p> | <p>The Regulation and Quality Improvement Authority. Audit of discharge of children on long-term ventilation<br/> <a href="https://www.rqia.org.uk/RQIA/files/a8/a871fa4d-6cda-41cb-8073-4ce93ffb285a.pdf">https://www.rqia.org.uk/RQIA/files/a8/a871fa4d-6cda-41cb-8073-4ce93ffb285a.pdf</a></p> |
| 12 | <p><b>Optimise the frequency of clinical review on an individual basis, for those on long-term ventilation who are at an increased risk of admission*</b></p> <p><i>*including people established on LTV &lt; 2 years and those who have had an unplanned admission in the previous 6 months</i></p> <p><b>Target audiences</b><br/> <b>LTV Services with support from Healthcare Professionals in all hospitals (including those that are not LTV centres), Primary Care and Social Care</b></p>   | <p><b>CHAPTER 5 – PAGE 62</b><br/> #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</p> <p><b>CHAPTER 5 – PAGE 67</b><br/> #53. Senior clinical review within 14 hours of admission was documented for 54/77 (70.1%) people who were admitted as an emergency – <i>Table 5.8</i></p> <p><b>CHAPTER 5 – PAGE 68</b><br/> #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<br/> #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) – <i>Table 5.9</i></p> <p><b>CHAPTER 5 – PAGE 70</b><br/> #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 – <i>Table 5.12</i><br/> #58. People who had been on LTV for &lt;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 – <i>Table 5.13</i></p>   |   |

# Method and data returns

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## 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  $\geq 1$  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).

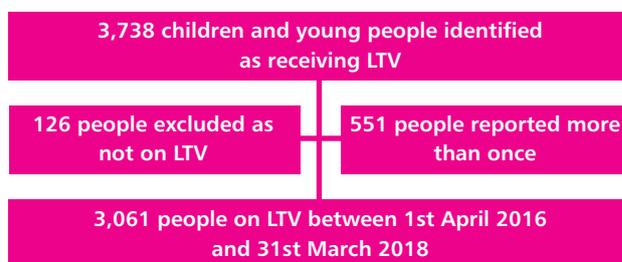


Figure 1.1. Data returned for the total study population of people on long-term ventilation

#### 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).

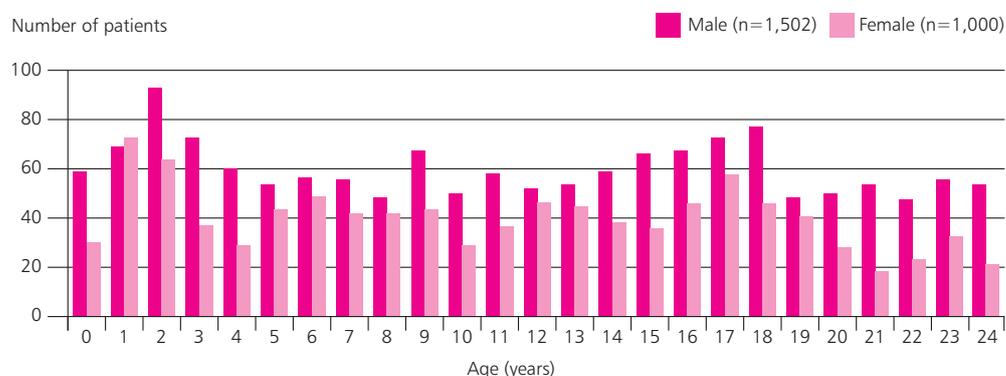


Figure 1.2 Age distribution by sex for the total study population (where both age and sex were available)

**Type of ventilation used**

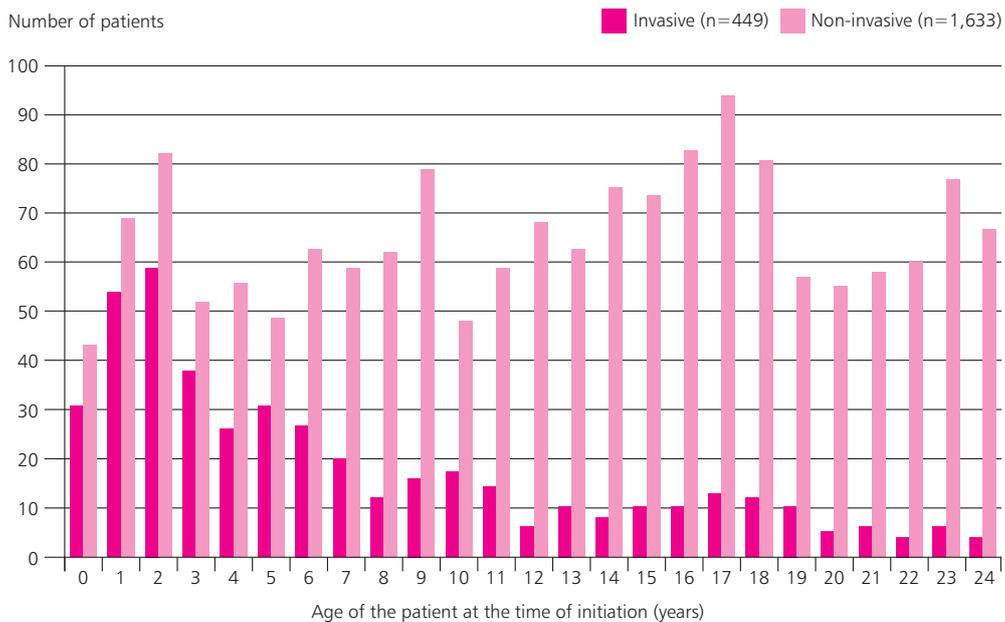
Table 1.1 shows that 475/2,190 (21.7%) people were known to be on invasive ventilation during the study period and 1,677/2,190 (76.6%) people on non-invasive ventilation. This changed very little over the study period.

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  |
| <b>Subtotal</b>   | <b>2,190</b>                      |      | <b>2,744</b>                      |      |
| Not answered  | 871                               |      | 317                               |      |
| <b>Total</b>  | <b>3,061</b>                      |      | <b>3,061</b>                      |      |

\*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  |
| <b>Subtotal</b>                         | <b>2,556</b>     |      |
| Not answered                            | 505              |      |
| <b>Total</b>                            | <b>3,061</b>     |      |

*\*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.

### Admission to hospital

**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  |
| <b>Subtotal</b>     | <b>1,852</b>     |      |
| Not answered        | 1,209            |      |
| <b>Total</b>        | <b>3,061</b>     |      |

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

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.

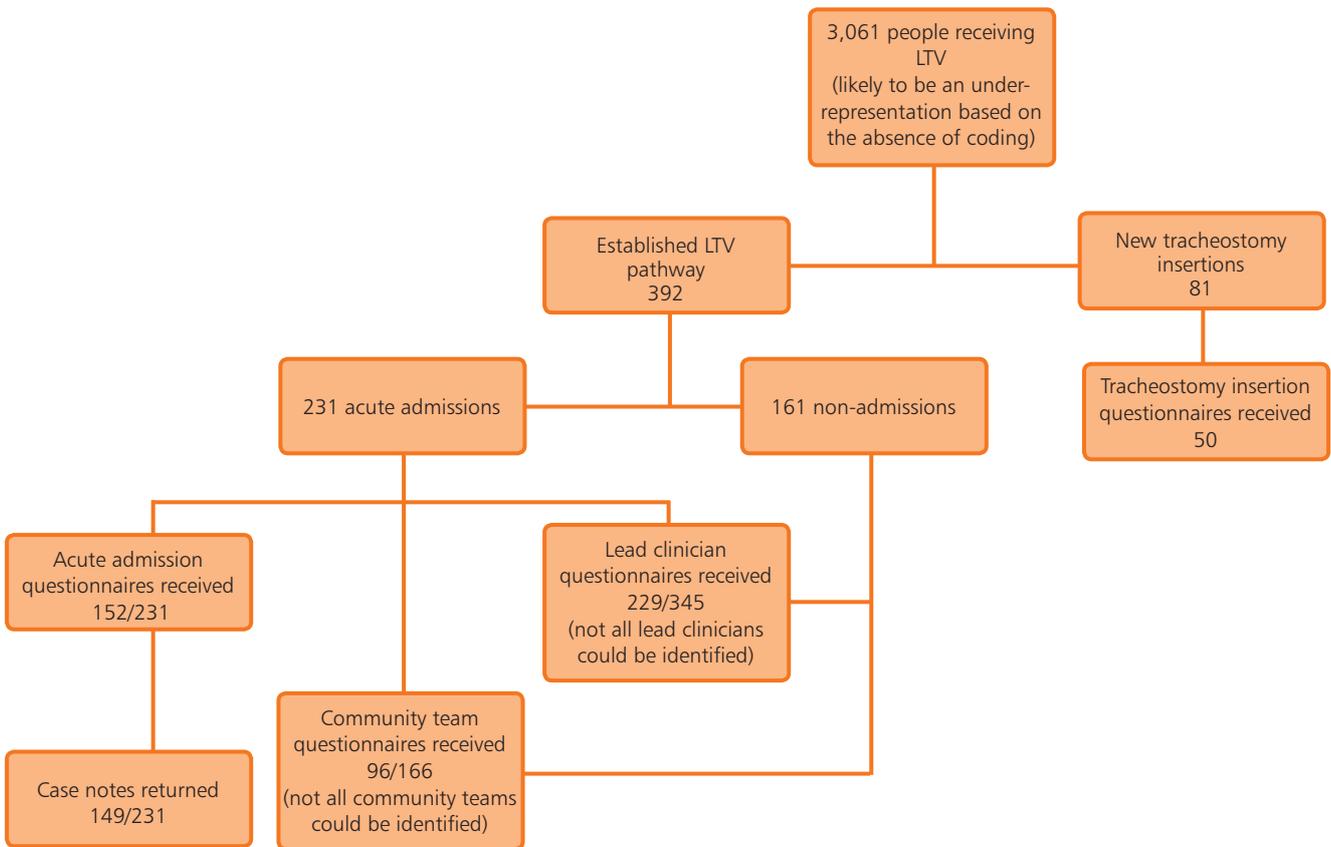
**Table 1.4 Acute admissions to hospital during the study period for the total study population**

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

*\*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 |
| <b>Subtotal</b> | <b>219</b>                   |      | <b>150</b>                    |      | <b>95</b>                             |      | <b>50</b>                            |      | <b>145</b>         |      |
| Unknown         | 10                           |      | 2                             |      | 1                                     |      | 0                                    |      | 4                  |      |
| <b>Total</b>    | <b>229</b>                   |      | <b>152</b>                    |      | <b>96</b>                             |      | <b>50</b>                            |      | <b>149</b>         |      |

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    |
| <b>Subtotal</b> | <b>227</b>                           |      | <b>141</b>                             |      | <b>95</b>                             |      | <b>147</b>               |      |
| Unknown         | 2                                    |      | 11                                     |      | 1                                     |      | 2                        |      |
| <b>Total</b>    | <b>229</b>                           |      | <b>152</b>                             |      | <b>96</b>                             |      | <b>149</b>               |      |

Tables 1.5 and 1.6 show the number of questionnaires returned, 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  |
| <b>Total</b>                          | <b>70</b>           |      | <b>70</b>           |      |

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 |
| <b>Total</b>    | <b>70</b>           |      | <b>70</b>           |      |

Organisational data

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

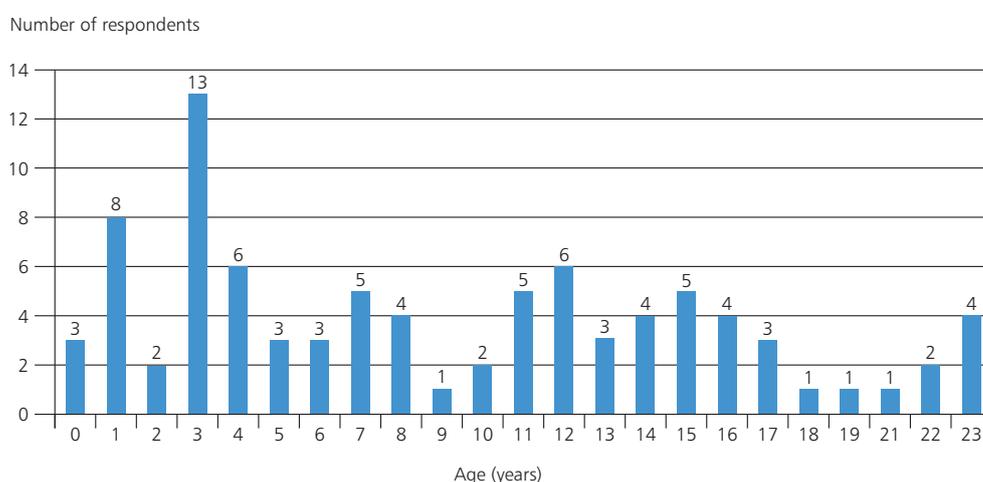
|                 | Acute hospitals  |      |                  |      | Community services |      |                  |      |
|-----------------|------------------|------|------------------|------|--------------------|------|------------------|------|
|                 | <18 years of age |      | ≥18 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 |
| <b>Subtotal</b> | <b>69</b>        |      | <b>69</b>        |      | <b>17</b>          |      | <b>8</b>         |      |
| Unknown         | 1                |      | 1                |      | 0                  |      | 1                |      |
| <b>Total</b>    | <b>70</b>        |      | <b>70</b>        |      | <b>17</b>          |      | <b>9</b>         |      |

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 |
| <b>Subtotal</b> | <b>70</b>        |      | <b>70</b>        |      | <b>16</b>          |      | <b>9</b>         |      |
| Unknown         | 0                |      | 0                |      | 1                  |      | 0                |      |
| <b>Total</b>    | <b>70</b>        |      | <b>70</b>        |      | <b>17</b>          |      | <b>9</b>         |      |

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.<sup>13</sup>

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  |
| <b>Total</b>                     | <b>243</b>            |      |

*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  |
| <b>Total</b>  | <b>243</b>            |      |

Answers may be multiple; n=243

Health and social care professional survey

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