

PATIENT REPORTED OUTCOME MEASURES STUDY OF CHILDREN ON LONG TERM VENTILATION 2011-2012

BACKGROUND

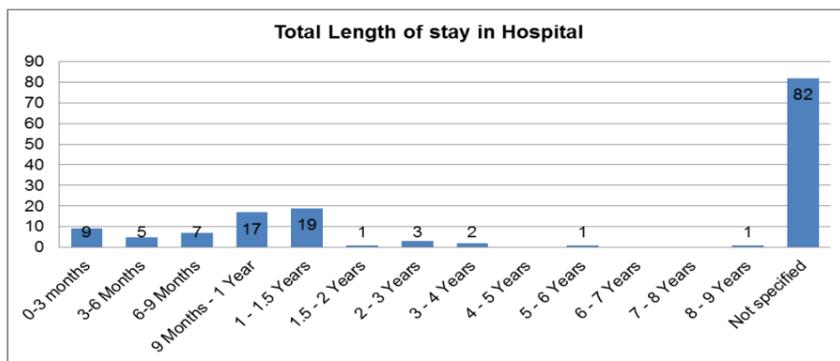
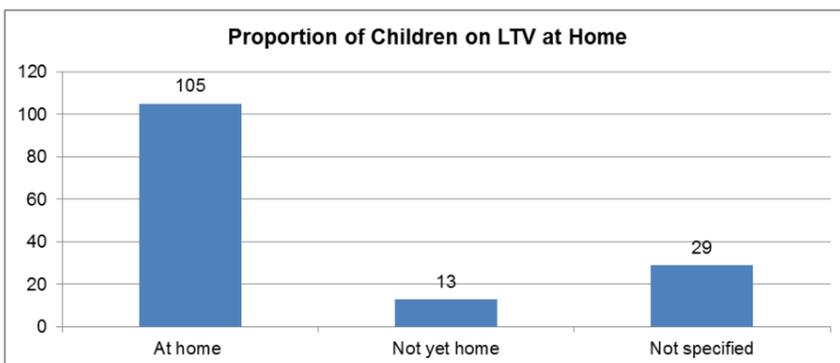
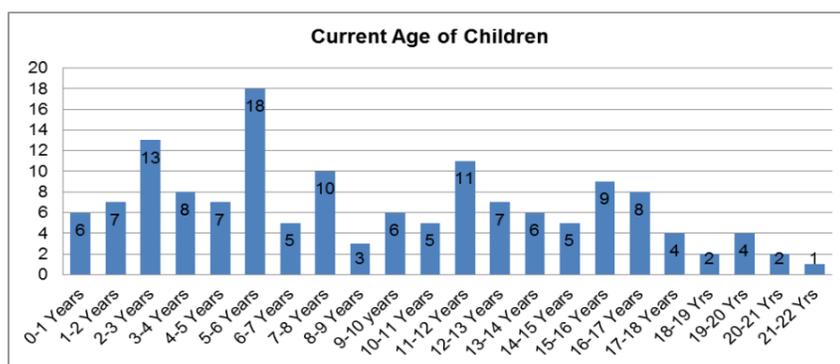
Changes in the ways in which children and young people with a wide range of complex disorders are cared for has meant that there has been a large increase over the past decade in numbers of children and young people receiving long term help with their breathing with a mechanical ventilator. The aim of this study was to collect information on the nature and quality of care and support offered to children, young people and their families, when ventilator support was initiated, and in the subsequent months and years during which it was continued – either in hospital or (increasingly commonly) at home. The information was collected to develop guidance on appropriate and ultimately auditable standards for the provision of such care.

ACTION

The questionnaire was developed with input from a broad range of professionals involved in the provision of LTV services (including paediatricians, intensivists, hospital and community based nurses), plus several families of children receiving LTV with a range of medical conditions. The study collected information dealing with three main areas:

1. The nature of the condition giving rise to the need for LTV, and basic demographic information about the child and family.
2. The processes from the time of recognition of the need for LTV until it was established at home or elsewhere.
3. The support provided to the family and their perceptions of the quality of care provided after establishment of LTV.

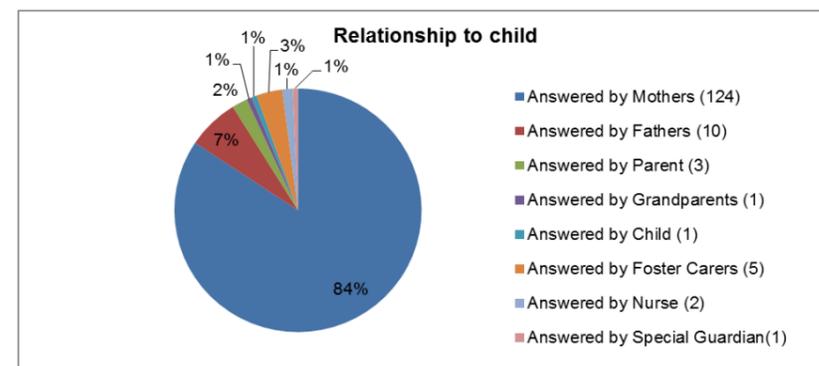
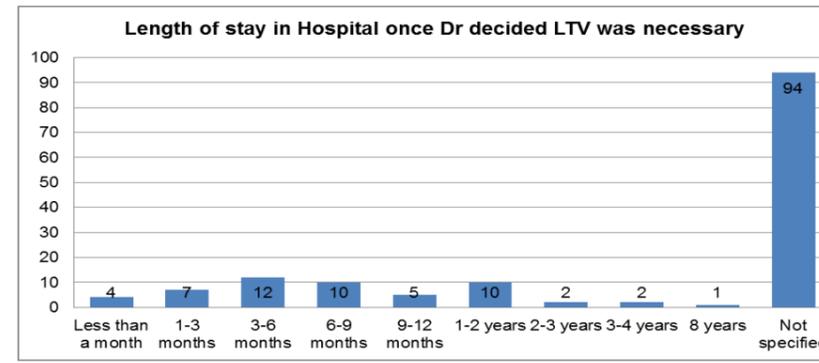
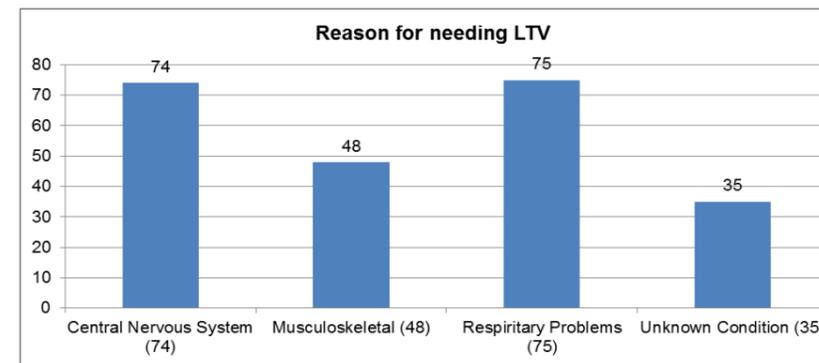
In each section parents were asked about their good and bad experiences as well as ways in which the service could be improved.



OUTCOMES

The study clearly showed the high level of commitment that the families of children on long-term ventilation have to sustain over prolonged periods of time. Despite the strains that such demands make on personal and family life, families generally remained positive and constructive in their suggestions as to how the services could be improved.

- ### URGENT IMPROVEMENT REQUIREMENTS
- ⇒ All units with patients on LTV should have a discharge planning coordinator involved early
 - ⇒ Commissioning bodies must agree early to an adequately funded care package: *in-patient care is more expensive to the NHS and blocks intensive care beds*
 - ⇒ Health must engage more closely with Social Care. *Failure of multiagency working caused breakdowns and children readmitted.*
 - ⇒ Improved provision of respite care. *Problems when family crisis or illness occurred, no back up so readmission.*
 - ⇒ Improved communications – between hospital and community based professionals.
 - ⇒ Concern over lack of continued training for parents and carers.



Acknowledgements
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