GROWING TOGETHER

Patient centred strategies for the development of LTV care

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Pan Thames Paediatric LTV Programme

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Connecting paediatric services

South Thames Paediatric Network
Transforming Healthcare for Children and Young People

ODN NORTHWEST SiC LTV PCC

East Midlands Paediatric Critical Care ODN

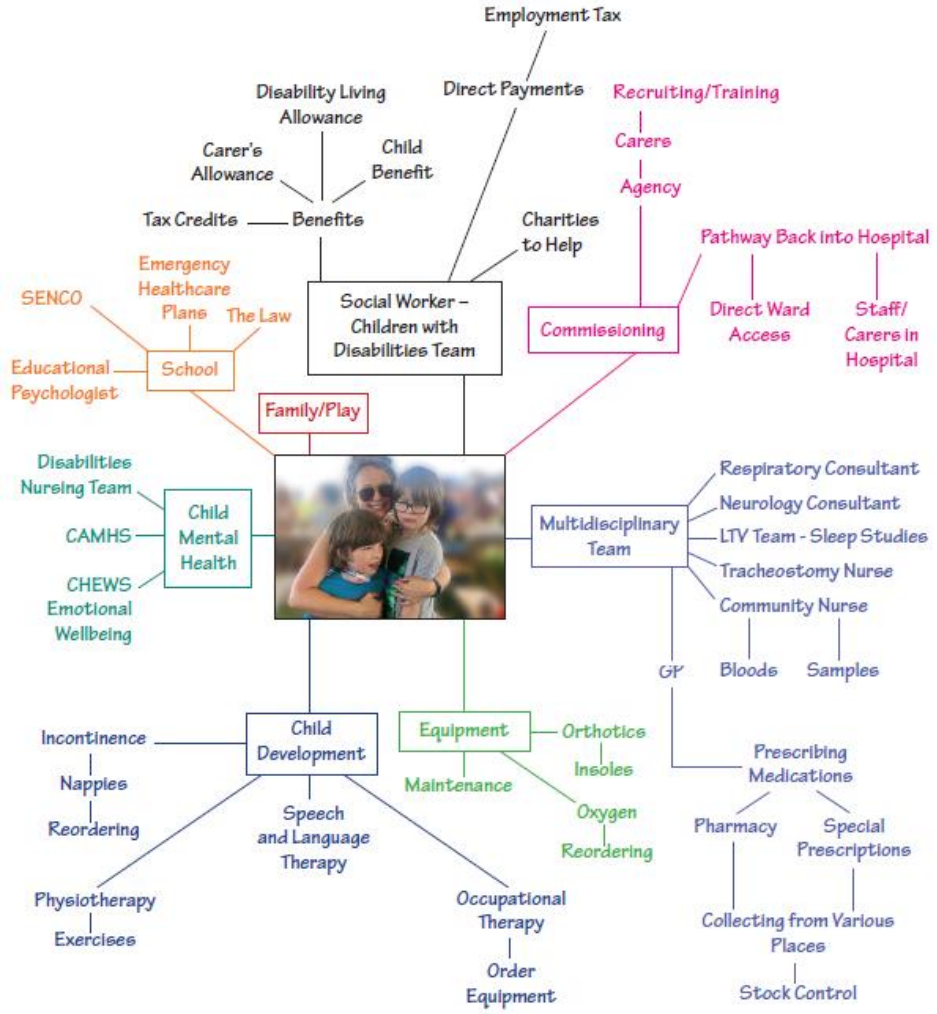
West Midlands Children's Network

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

Background

- The number of people receiving LTV in the UK was not known
  - Limited local or national data collection
  - No national procedure code
- Variation in underlying diagnosis
- Variation in ventilator support required
- Provision of care outside of the hospital setting
- Complex care pathway



> *"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*

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 between the 1st April 2016 – 31st March 2018

Objectives

- The quality of care received
- Multidisciplinary care
- Appropriateness of the location of care
- Transition to adult services
- The organisation of services
- Networks of care

Study methods

Data were collected from a number of sources:

- 1. Number of children and young people on LTV during the study
  - All patients under the care of an LTV service, or who were admitted any hospital over the two-year study data collection period - 1st April 2016 to 31st March 2018 inclusive.

Study methods

- 2. Sampled study population for the clinical peer review process

- Established
  - Lead clinician questionnaire
  - Community team clinical questionnaire
  - Acute admission questionnaire
  - Case notes

- New tracheostomy insertions
  - Tracheostomy insertion questionnaire

Study methods

- 3. Organisational data
  - Paediatric services
  - Adult services

- 4. Service user and parent carer online survey and focus groups
  - Online survey
  - Focus groups

- 5. Health and social care professional online survey and interviews
  - Online survey
  - Interviews

Data returns: Number of CYP reported

3,738 children and young people identified as receiving LTV

126 people excluded as not on LTV

551 people reported more than once

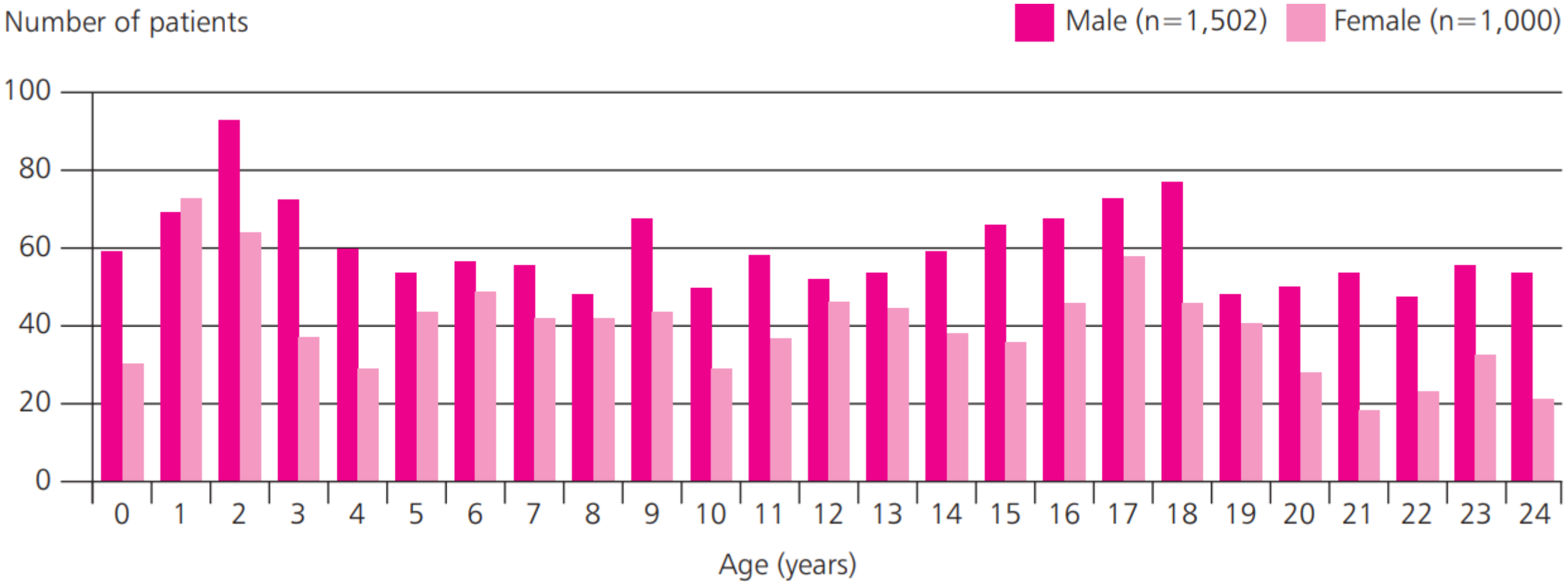
3,061 people on LTV between 1st April 2016 and 31st March 2018

Data returns: Number of CYP reported

Jardine et al, 1999		Wallis et al, 2010			NCEPOD 2020		
	n		n	%		n	%
Craniofacial syndrome	9	Upper Airway Obstruction	256	27.4	Upper Airway Obstruction	791	30.9
Neuromuscular disease	62	Musculoskeletal	402	43.1	Musculoskeletal	751	29.4
Congenital central hypoventilation syndrome & spinal injury	34	Central nervous system	168	18.0	Central Nervous System	630	24.6
Bronchopulmonary dysplasia	6	Chronic Respiratory Disease	37	4.0	Chronic Respiratory Disease	227	8.9
NA	0	Other respiratory	50	5.4	NA	0	0.0
Other	25	Unclassified	20	2.1	Other	157	6.1
Subtotal	**136**	**Subtotal**	**933**		**Subtotal**	**2556**	
Not answered	0	Not answered	0		Not answered	505	
Total	**136**	**Total**	**933**		**Total**	**3061**	

Trends in Long-Term Ventilation Care in U.K. Children and Young People-Further Consideration Required for Pediatric Critical Care Services. 2023. Paediatric Critical Care Medicine: 24(9)

Age and sex


Number of patients
Male (n=1,502)
Female (n=1,000)
100
80
60
40
20
0
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24
Age (years)

Data returns: Number of CYP reported

"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

"Transition is awful. Start very, very early, try and get all your questions sorted, and fight for everything"

Service user/parent carer

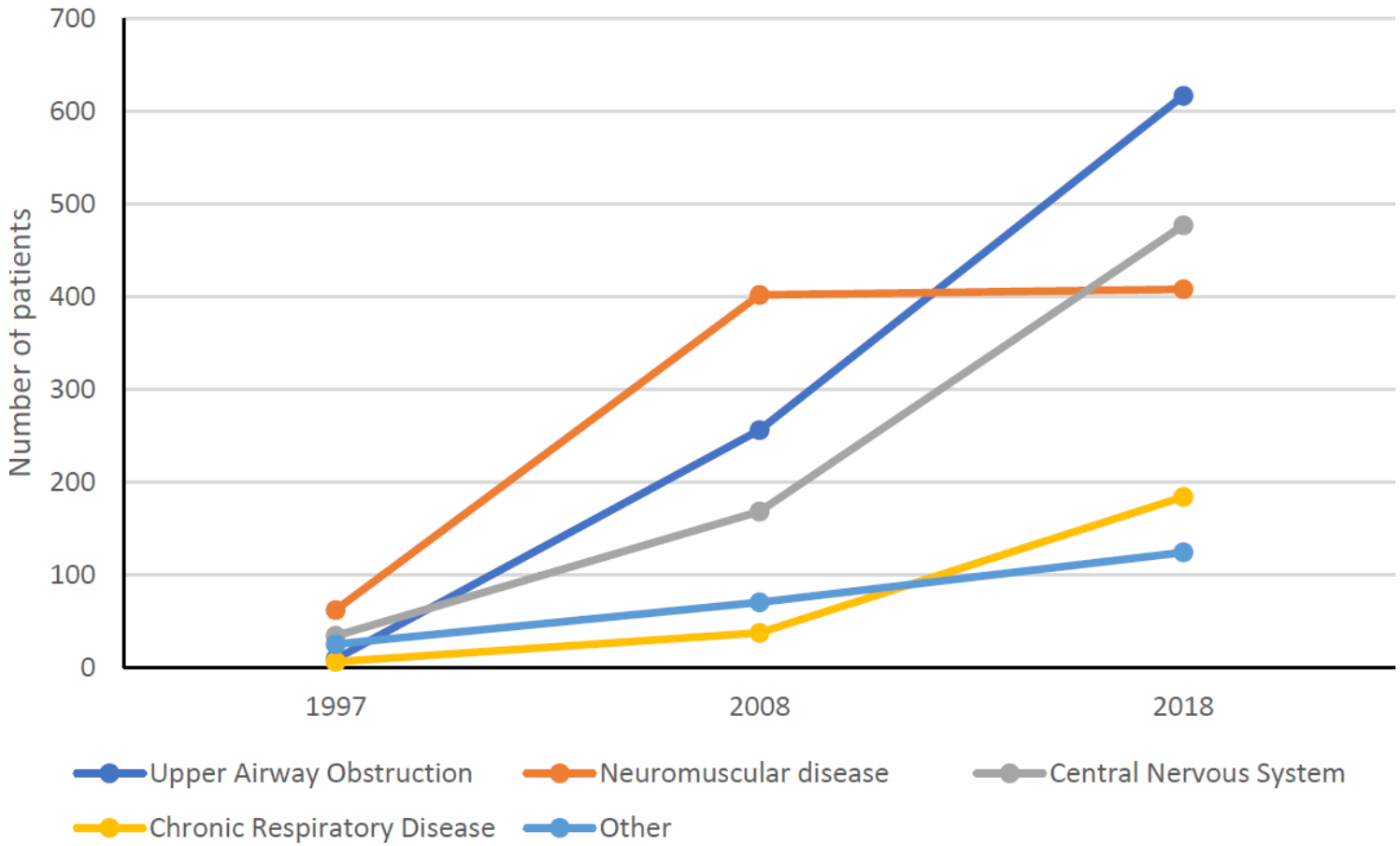
Type of ventilation received

	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**	

Underlying condition

	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**	

Underlying condition



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Duration of daily ventilation

	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**	

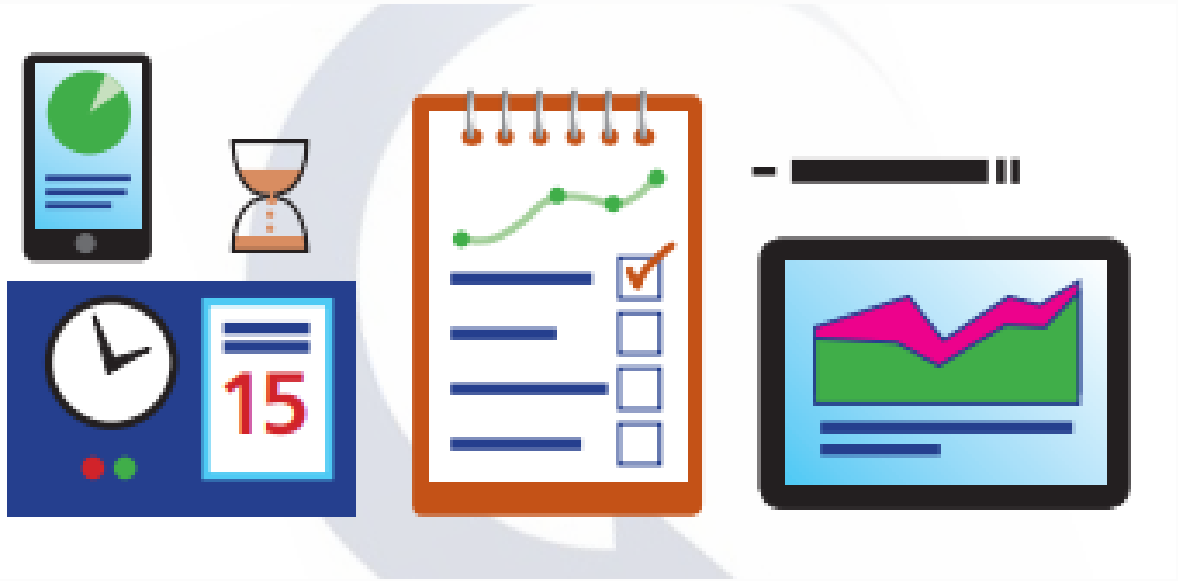
Admission to hospital

	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**	

Key messages

- Service planning and commissioning of integrated services
- Multidisciplinary care
- Emergency healthcare plans
- Discharge planning
- Transition from child to adult services

Service planning



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.

Service planning

- Data indicated there was variation in:
  - Commissioning arrangements
  - Access to services i.e., respite care
  - Multidisciplinary team members
  - Discharge arrangements

"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

"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

"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

"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

Multidisciplinary care

The MULTIDISCIPLINARY TEAM should work across community and hospital networks and include a specialist in tracheostomy care where applicable

Multidisciplinary care

- Data indicated there was variation in:
  - Team working arrangements
  - Clinical leadership

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.

Emergency healthcare plans

Personalised EMERGENCY HEALTHCARE PLANS should be reviewed annually and after hospital admissions, and form part of the hand-held record

Emergency healthcare plans

- Data indicated there was variation in:
  - The use of fast-track admission plans
  - The use of emergency healthcare plans

> ***"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***

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.

Discharge arrangements

DISCHARGE ARRANGEMENTS for people established on LTV who are admitted to hospital should:

- Commence on admission
- Be clearly documented
- Involve the usual LTV team
- Document any changes to usual care

Discharge arrangements

- Data indicated there was variation in:
  - The timing of discharge planning
  - Who was involved in discharge planning
  - The provision of revised care plans at discharge from hospital

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 .

Transition

TRANSITION PLANNING should include an identifiable clinical and executive lead, and form part of an integrated care pathway

Transition

- Data indicated there was variation in:
  - Transition planning
  - Access to joint clinics
  - Clinical leadership for transition

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.

Recommendations

7 relate to service planning and commissioning

- Integration of care pathways
- Identification of patients and reliable data
- MDT which works across Networks
- Shared Decision Making
- Planning for Transition
- Structured training and resources
- Standardise equipment issues

5 relate to routine clinical care

- Personalised Emergency Health Plan
- Age-appropriate emergency care
- Good ventilation care on admission
- High quality discharge arrangements
- Optimise frequency of clinical review

Report and supporting tools

- Full report
- Summary report
- Infographic
- Recommendation checklist
- Audit tool
- Fishbone diagram
- Slide set
- Commissioners guide