

Long term Ventilation- challenges and rewards

Umair Khan

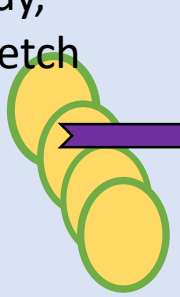
Consultant in Acute Paediatrics and PICU

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LTV- the definition

- “Any child who continues to require a mechanical aid for breathing, after failure to wean, three months after initially requiring breathing support.”
- Support ranges from:
 - Simple mask continuous positive airway pressure (CPAP) during sleep to full 24 hour positive pressure support via tracheostomy. (Invasive LTV)
- 3 Levels-
- Level 1 (High)
- Level 2 (Severe)
- Level 3 (Priority)

Various receptors-
Carotid body,
O₂; pH; stretch
receptors



Conscious
respiration

Cerebral
Cortex

Automatic
Respiration

Brain
stem
(Pons;
medulla)

Upper airway muscles

CSC

DIAPHRAGM

Phrenic
nerve

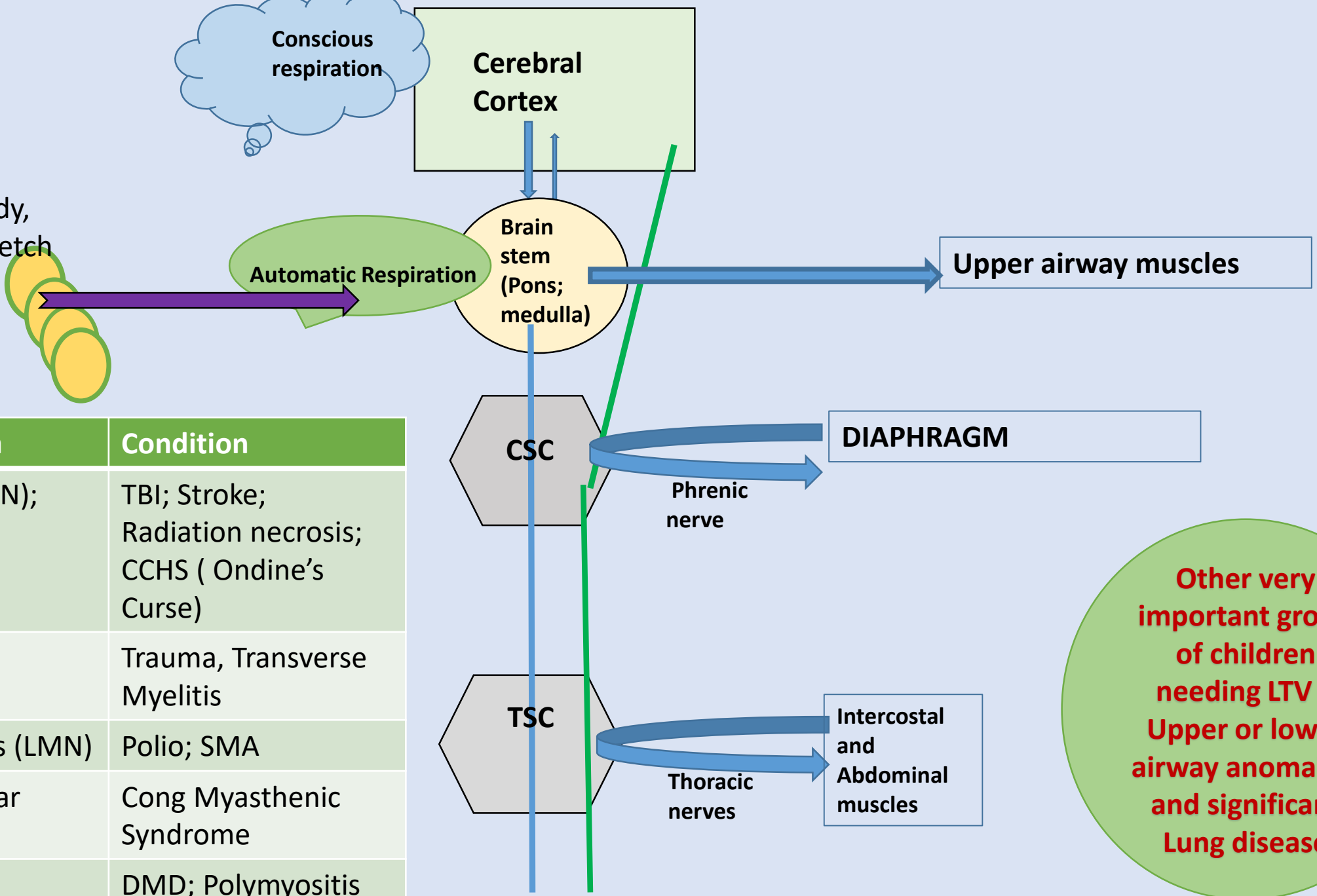
TSC

Intercostal
and
Abdominal
muscles

Thoracic
nerves

Other very
important group
of children
needing LTV –
Upper or lower
airway anomalies
and significant
Lung disease

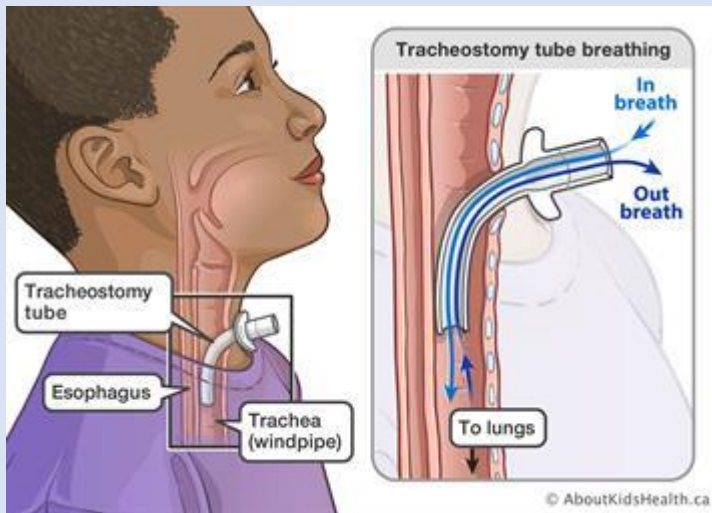
Problem Area	Condition
Cortex (&UMN); Brainstem	TBI; Stroke; Radiation necrosis; CCHS (Ondine's Curse)
Spinal Cord	Trauma, Transverse Myelitis
Ant Horn Cells (LMN)	Polio; SMA
Neuromuscular junction	Cong Myasthenic Syndrome
Muscle	DMD; Polymyositis



CPAP and NIV Bi Level support : Interface and Equipment



Invasive ventilation

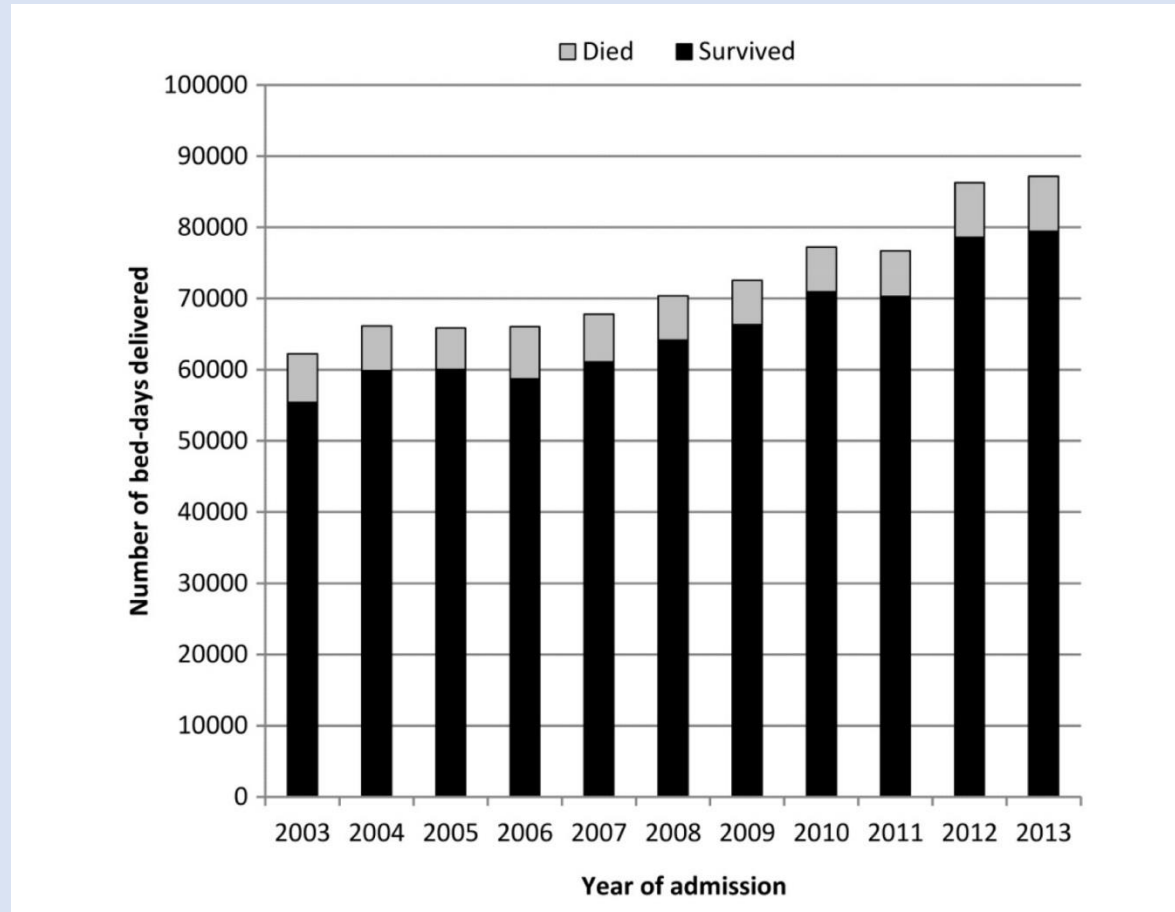


Tracheostomy image from - <https://www.aboutkidshealth.ca/article?contentid=3264&language=english>

Increasing PICU admissions; Longer PICU stay; More survivors.

(Plunkett A, Parslow RC. Arch Dis Child 2016;101:798–802. doi:10.1136/archdischild-2015-309592)

Over 10 yrs increased from about 60,000 bed days in 2003 to about 90,000 in 2013.

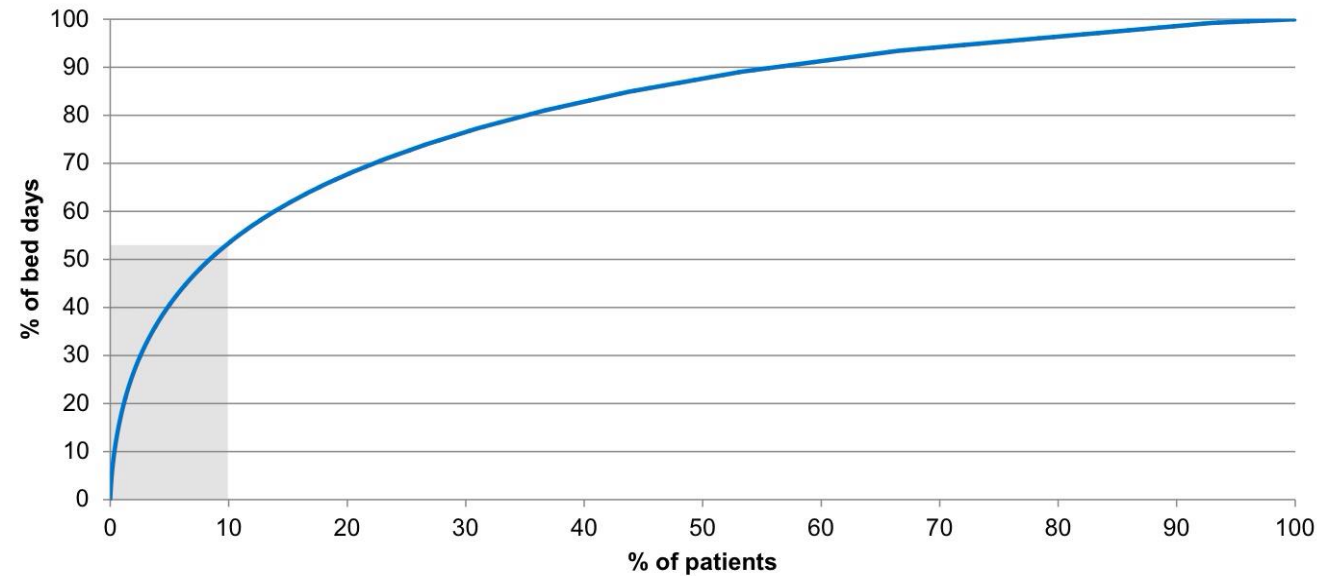


3.7 Ten per cent of children admitted to PICUs use more than half of resources

2011 to 2015 data from PICANet shows that 10% of children admitted to PICUs used over 50% of PICU resources . The review will be considering the nature of this cohort of patients, which is likely to be children with long-term, complex needs, and whether alternative care settings could benefit these children and their families as well as help to optimise the use of PICU beds. This is particularly important given the potential for further increased demand for critical care from children who have a life-limiting illness but who are surviving longer.

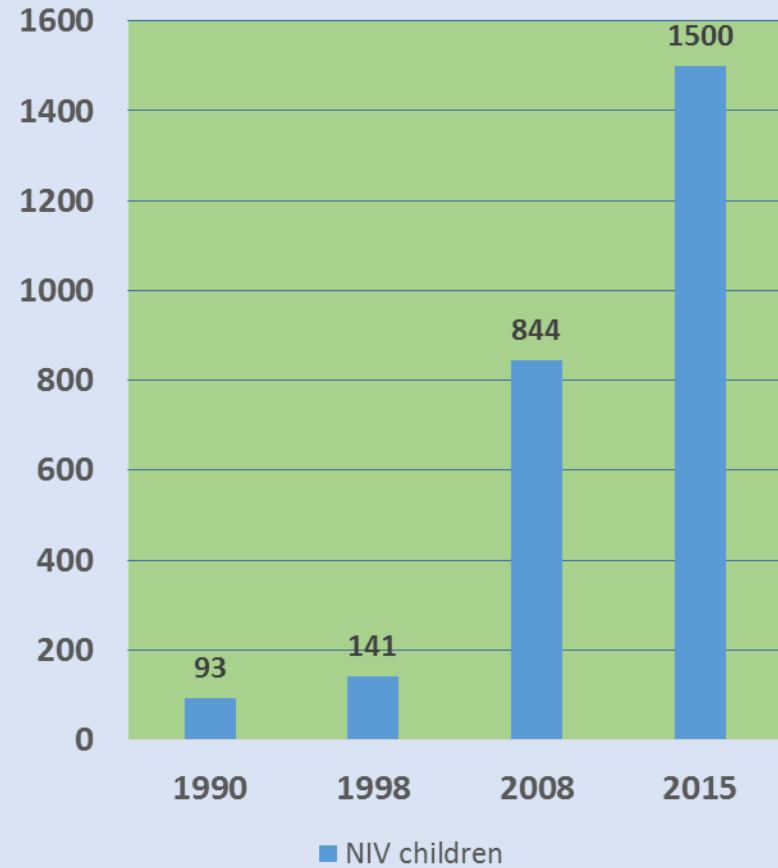
50% of bed days for 10% of long term ventilation/ complex need patients .

Percentage of bed days consumed by percentage of patients, 2011 to 2015



LTV – Exact UK numbers unknown

LTV in England and Wales
=1500

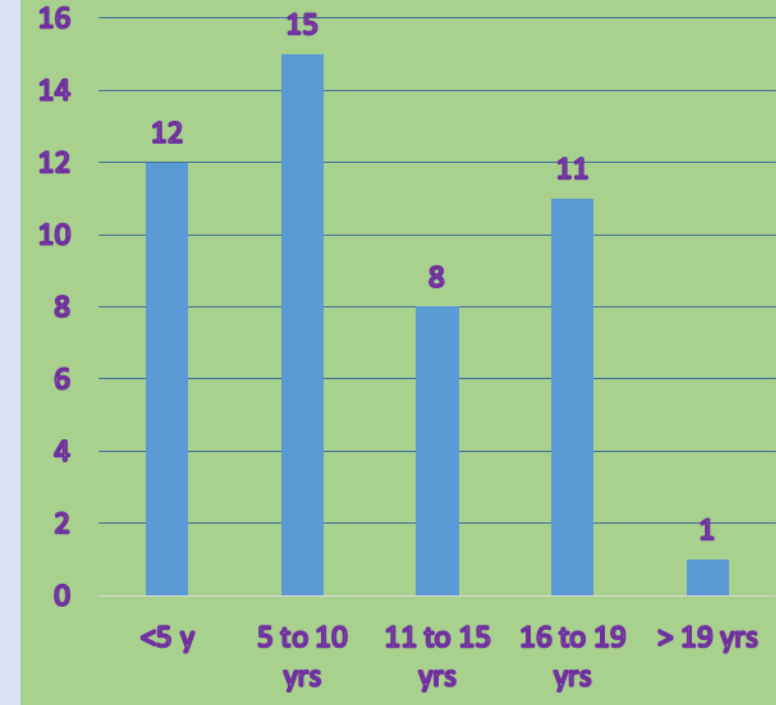


Anticipated increase by 80-100
invasive LTV children per year
across the UK

Scotland = 209

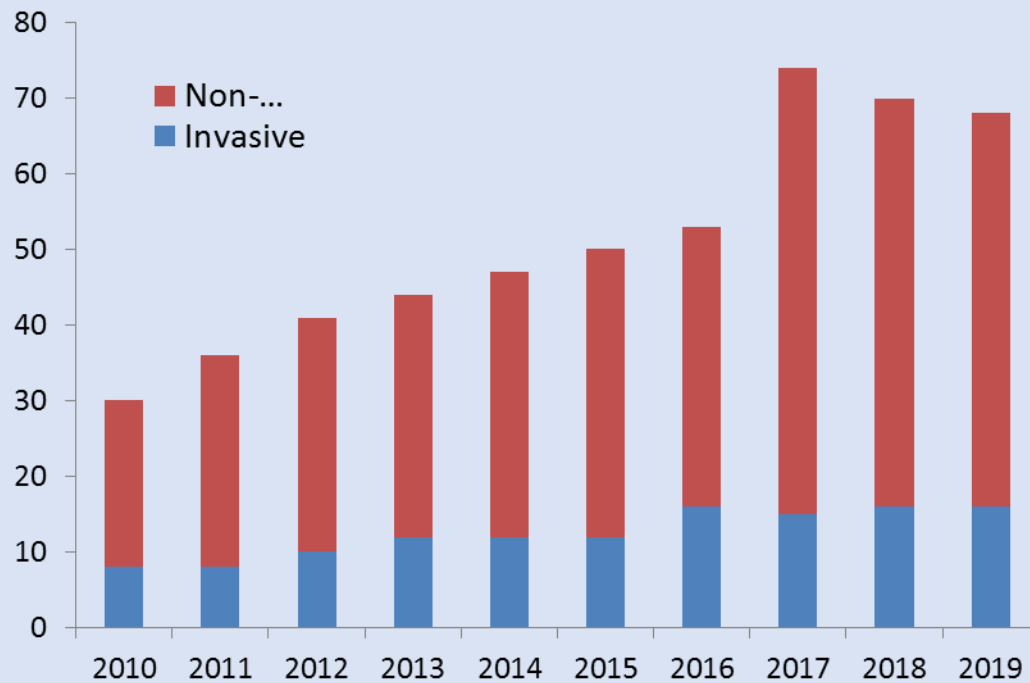
West	135
East	74

LTV in Northern Ireland = 47
children (age wise)

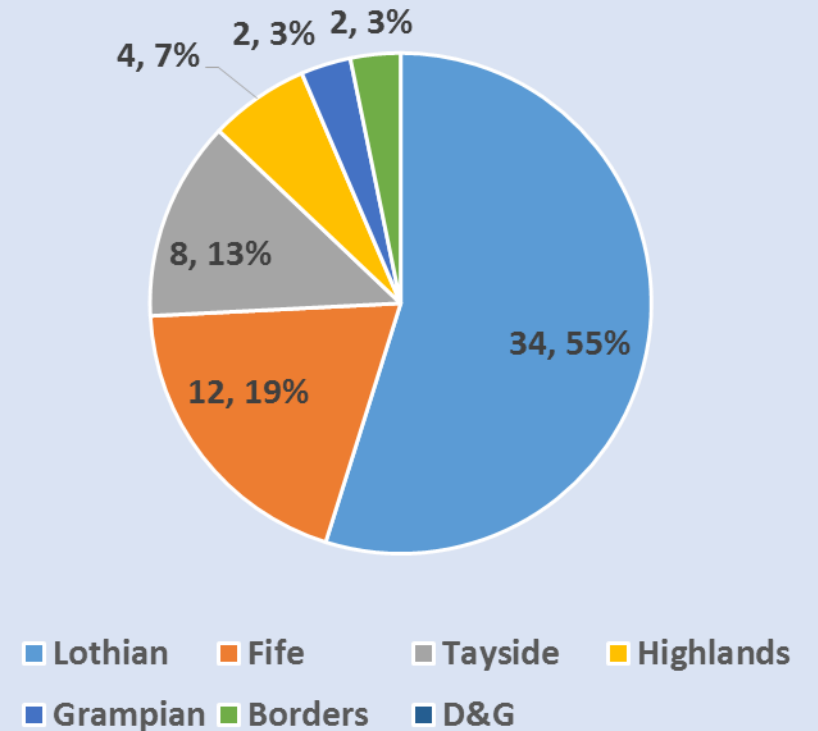


LTV numbers- RHSC Edinburgh : NIV (CPAP & BiPAP) 58;
Trachy (Invasive) 16.

140% increase over 10 years



Across East of Scotland..



Data courtesy of Dr Catherine McDougall and Linda McCarthy

Hospital to Home – a complex process

Invasive LTV (tracheostomy) patients : average 6-9 months (can take up to 12 months)

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Long-term ventilation support

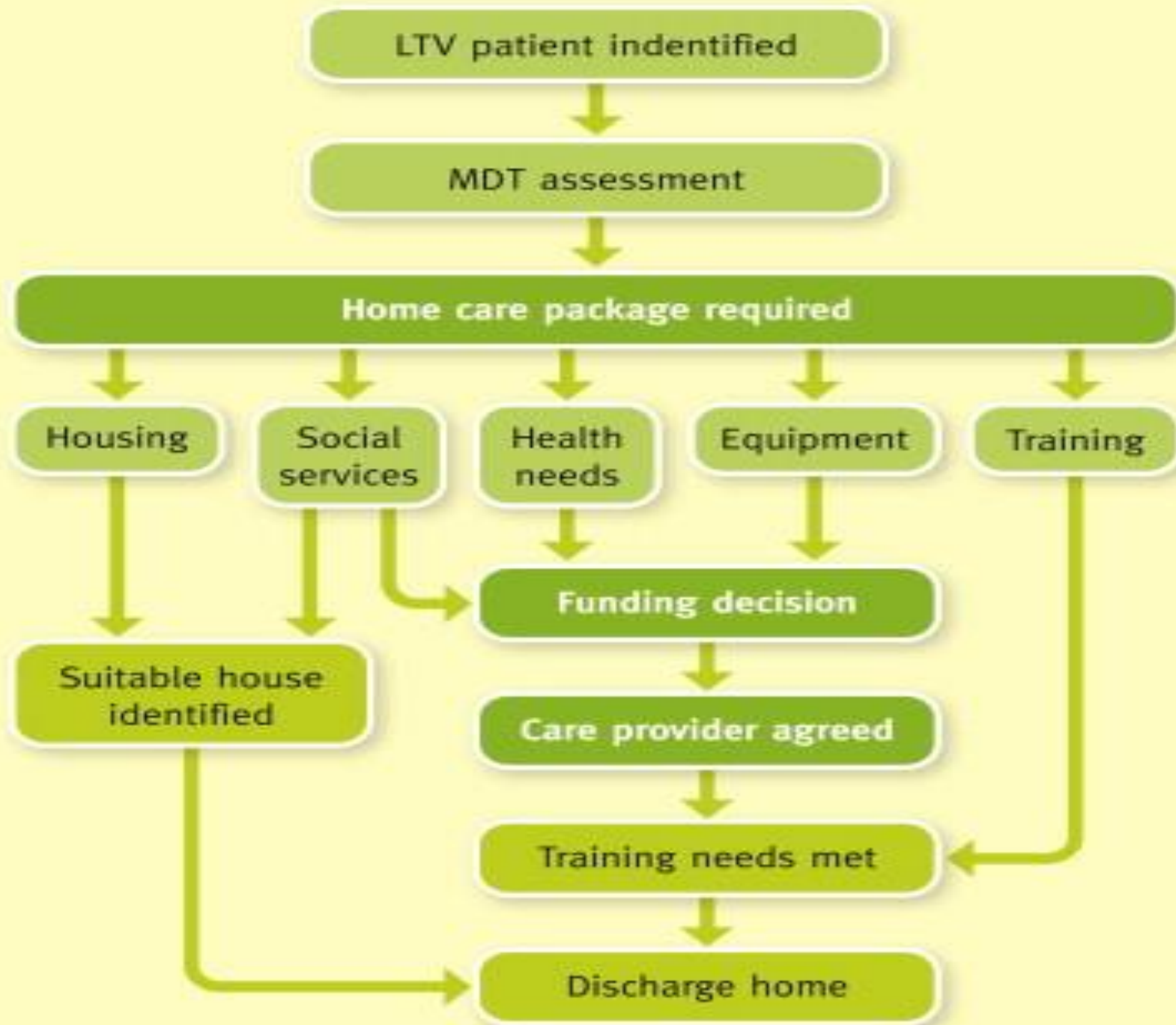
New research suggests many children on long-term ventilation support end up staying on intensive care wards in hospital for years after they are well enough to leave.

The charity, Breathe On UK, says the biggest reason for this is a lack of specially trained NHS nurses who can provide care in the home.

Matthew Hill reports.

🕒 20 Jan 2013

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- Oxygen
- Humidification
- Suction
- Back up ventilators/ equipment (lifetime costs)
- Escalation plans
- Multidisciplinary team input
- Tracheostomy management / complications
- Ongoing training needs
- Unusual circumstances e.g. Swimming(!), travel, etc

Table 3 Comparison of total costs of 12 months support in different hospitals and home-care settings, 2002 prices (Noyes, 2004)

Model	A	B	C	D	E	F	G	H	I	J	K	L
Package	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months	12 months
	Paediatric intensive care unit @ £1700 per 24 hrs	High-dependency Long-term ventilation unit @ £800 per 24 hrs	Children's ward @ £398 per 24 hrs	24-hour home care E grade nurses £184,987 Team leader Grade F nurse 0.2 WTE £8,385	24-hour home care 50% E grade nurses £92,494 B grade HO £53,000 Team leader Grade F Nurse 0.2 WTE £8,385	24-hour home care B grade HCA £106,306 Team leader	24-hour home care LA home-care worker £101,708 Team leader	12-hour night home care B grade HCA £57,583 Team leader Grade F nurse 0.2 WTE £8,385	12-hour day care B grade HCA	Parent unpaid carers	High-dependency nursing home for disabled young adults @ £1,136 per week	'Home for Life' Royal Hospital for Neuro-disability Ventilator Unit for young people and adults @ £3,000 per week for basic care in outer London
Nursing and personal care ---				£193,372	£154,032	£114,691	£110,093	£65,967	£57,108	£0	£59,072	£156,000
Equipment *				£7,220	£7,220	£7,220	£7,220	£7,220	£7,220	£7,220	£7,220	£7,220
Hospital services **	£620,500	£292,000	£145,270	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541	£18,541
Community health services #	£647	£647	£647	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519	£2,519
Primary care services +				£866	£866	£866	£866	£866	£866	£866	£866	£866
Pharmacy ***				£2,007	£2,007	£2,007	£2,007	£2,007	£2,007	£2,007	£2,007	£2,007
Disposable equipment and supplies****				£8,132	£8,132	£8,132	£8,132	£8,132	£8,132	£8,132	£8,132	included
Social services ##	£5,412	£5,412	£5,412	£56	£56	£56	£56	£56	£56	£56	£56	£56
Education ++	£3,829	£3,829	£3,829	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142	£7,142
TOTAL	£630,388	£301,888	£155,158	£239,855	£200,515	£161,174	£156,576	£112,450	£103,591	£46,483	£105,555	£194,351

12 months PICU £630,000/yr

12 hr night home carer £ 112,450/ yr

Parent unpaid carers = £46,483/ yr

From Hospital to Home , Noyes et al 2004
<http://data.parliament.uk/DepositedPapers/Files/DEP2009-1604/DEP2009-1604.pdf>

Significant Hidden costs

- Financial burden:
Lost wages of parent
Living costs away from home
Increased child care costs for siblings
- Emotional Psychological impact :
Isolation / loss of control
Family separation / impact on siblings
Reliance on “strangers” (in your home)
Anxiety for the future
Grieving the loss

Children who are Long Term Ventilated – Pathfinder Project

Engaging with Families and Children / Young People

*An independent quality improvement review
by the Patient Experience Network*

For
NHS England

Prepared by Ruth Evans

September 2014

A challenging task-
Both:
Care Delivery
+
Crucially – in
Decision making!



OPEN ACCESS

Original article

Analysis of paediatric long-term ventilation incidents in the community

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ABSTRACT

Aim To describe the nature and causes of reported patient safety incidents relating to care in the community for children dependent on long-term ventilation with the further aim of improving safety.

Methods We undertook an analysis of patient safety incident data relating to long-term ventilation in the community using incident reports from England and Wales' National Reporting and Learning System occurring between January 2013 and December 2017. Manual screening by two authors identified 220 incidents which met the inclusion criteria. The free text for each report was descriptively analysed to identify the problems in the delivery of care, the contributory factors and the patient outcome.

Results Common problems in the delivery of care included issues with faulty equipment and the availability of equipment, and concerns around staff competency. There was a clearly stated harm to the child in 89 incidents (40%). Contributory factors included staff shortages, out of hours care, and issues with packaging and instructions for equipment.

Conclusions This study identifies a range of problems relating to long-term ventilation in the community, some

What is already known on this topic

- ▶ The number of children on long-term ventilation cared for at home is rapidly increasing.
- ▶ There are significant risks in long-term ventilation that need to be carefully managed.
- ▶ Little is known about the safety of care for children on long-term ventilation in the community.

What this study adds

- ▶ This study identifies a range of problems in care and underlying factors experienced by children on long-term ventilation at home.
- ▶ Priorities for improvement are training of staff, maintenance and availability of equipment, support for families and improving coordination of care.

Arch Dis Child first published as 10.1136/archdischild-2019-017965 on 17 December 2019. Doi

News > Health

Safety fears for hundreds of 'hidden' children on ventilators

'There is a dwindling supply of staff and an increasing number of patients,' top doctor warns

Shaun Lintern Health Correspondent | @ShaunLintern |

Wednesday 18 December 2019 09:27 |



More than 220 safety incidents were reported to the NHS involving children reliant on ventilators at home between 2013 and 2017. (Getty Images/BlackPhoto)

Experts have warned hundreds of "hidden" children who rely on machines to help them breathe at home are at significant risk of harm due to staff shortages, poor equipment and a lack of training.

The number of children who rely on long-term ventilation is rising but new research has shown the dangers they face with more than 220 safety incidents reported to the NHS between 2013 and 2017.



indy100

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- Americans are actually gongling 'what is India' as Trump makes visit
- Why people are accusing Kim Kardashian of blackfishing
- A study by Harvard University has found an weird marker of

Analysis of safety incident data of LTV patients from England and Wales' National Reporting and Learning System January 2013 - December 2017.

Results - Problems in care delivery : issues with faulty equipment + concerns around staff competency.
220 total incidents - Clearly stated harm to the child in 89 incidents (40%).
Identified reasons - staff shortages, out of hours care, and issues with packaging and instructions for equipment.

From Scotstar retrieval website

<https://www.snprs.scot.nhs.uk/>

Scotland- 2 PICUs;
4 HDUs

Reliant on
excellent
retrieval service

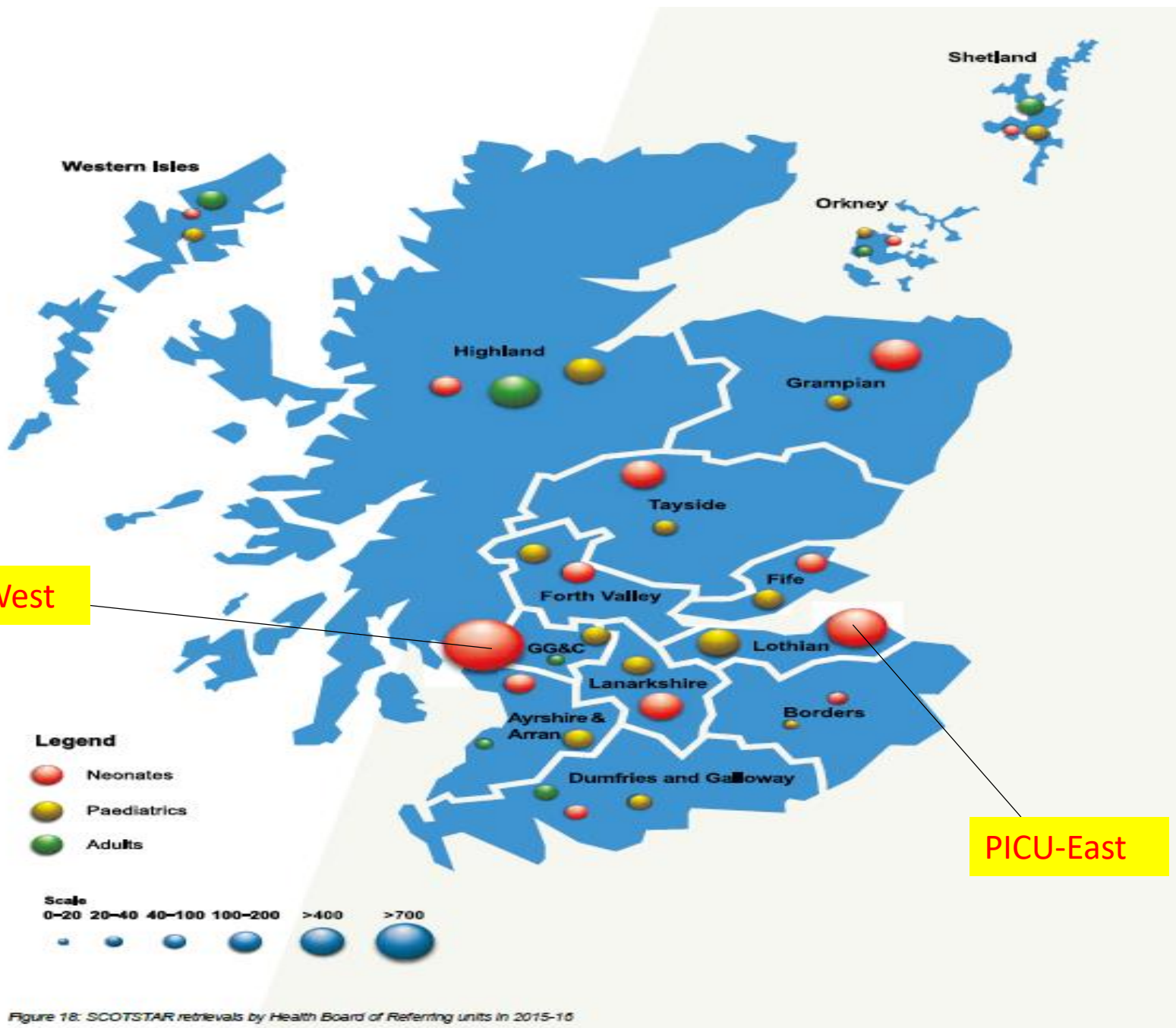


Figure 18: SCOTSTAR retrievals by Health Board of Referring units in 2015-16

The challenge in decision making !

US study - 2015 to 2017; small numbers (parents of 25 children)- 52% expressed regret at decision within 2 weeks; 72% by 3 months.

Conclusions:

There is parental conflict with worsening regret and quality of life over time post tracheostomy.

Strategies to reduce contributing factors may improve parental outcomes after this life-changing decision.

Parental Conflict, Regret, and Short-term Impact on Quality of Life in Tracheostomy Decision-Making

Tessie W. October, MD, MPH^{1,2}; Amy H. Jones, MD³; Hannah Greenlick Michals, RN, CPNP³; Lauren M. Hebert, MD^{4,5}; Jiji Jiang, MS⁶; Jichuan Wang, PhD⁶

Objectives: The prevalence of tracheostomy-dependence in critically ill children is increasing in the United States. We do not know the impact of this decision on parental outcomes. We aimed to determine the prevalence of decisional conflict and regret and explore the impact on quality of life among parents considering tracheostomy placement for their child.

Subjects: Parents facing tracheostomy decision for their child.

Design: Prospective, mixed-methods longitudinal study.

Setting: PICU, cardiac ICU, and neonatal ICU of a single quaternary medical center.

Interventions: None.

Measurements and Main Results: Parents completed a decisional conflict survey at the time of tracheostomy decision and decisional

regret and quality of life surveys at 2 weeks and 3 months after the decision regarding tracheostomy placement was made. We enrolled 39 parents, of which 25 completed surveys at all three time points. Thirty-five of 39 (89.7%) reported at least some decisional conflict, most commonly from feeling uninformed and pressured to make a decision. At 2 weeks, 13 of 25 parents (52%) reported regret, which increased to 18 of 25 participants (72%) at 3 months. Regret stemmed from feeling uninformed, ill-timed timing of placement, and perceptions of inadequate medical care. At 2 weeks, the quality of life score was in the mid-range, 78.8 (SD 13.8) and decreased to 75.5 (SD 14.2) at 3 months. Quality of life was impacted by the overwhelming medical care and complexity of caring for a child with a tracheostomy, financial burden, and effect on parent's psychosocial health.

Conclusions: The decision to pursue tracheostomy among parents of critically ill children is fraught with conflict with worsening regret and quality of life over time. Strategies to reduce contributing factors may improve parental outcomes after this life-changing decision. (*Pediatr Crit Care Med* 2020; 21:136–142)

Key Words: child, intensive care; clinical decision-making; critical illness; ethics, research; intensive care units, pediatric

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Theme	Sample Quotes
No choice	<p>"If I knew there was any other option, I would have taken it. We chose the tracheostomy as a last resort to save our baby's life."</p> <p>"As it was explained to my husband and I in our 'family meeting' with the attending Neonatologist, the trach was the only option for [our son] to ever be able to leave the hospital. If we chose to not do the surgery, we would be 'letting him go' and he would not survive without the trach and ventilator. Looking back, I feel that [our son's] condition was unfairly evaluated as more dire than it actually is. I still wonder if the trach would have been necessary if [our son's] condition continued to improve."</p>
Uninformed	<p>"I don't know what the options are. What are the benefits of a trach vs. intubation? Is there a possibility she might get better on her own?"</p> <p>"We had to do a lot of research online on our own so it has taken me long to decide because I do not feel informed."</p>
Maintaining hope	<p>"My son may need a trach but we are not sure yet. I want to do what's best for my son but I also hope he does not need a trach."</p> <p>"The doctors would not give me a full spectrum of his possible prognoses, only the worst case scenarios. When asked about the best case, they avoided the question. Not because best case scenarios may not exist, but because even talking about best case scenarios might mean that, we the parents, would ignore the other end of the spectrum. As a result, any decision I made would not be informed."</p>
Putting my child's needs above my own	<p>"I am not as sure about what to do as his mother. I want what's best for him."</p> <p>"I know my son should not get a trach ... I am making the decision that is best for my son, NOT the decision that is best for me."</p>
Felt pressured	<p>"The doctors had already made the decision to place the trach. All discussions and answers to questions were designed to convince me to agree with their decision."</p> <p>It would be better if they (physicians) didn't mention it so many times, maybe tighten up the communication channels and not have so many different people saying the same thing. I understand it is their job to take care of [my son] medically, but they should also be aware of our family's emotions.</p>
Weighing options without judgment	<p>"I changed my decision between Friday and Monday from trach to no trach and I felt judged by the new nurse ... she treated me like I hadn't thought at all about it which is clearly NOT the case. I prayed, paced, and cried about the decision, so it set me into orbit that she thought I could be so careless!"</p> <p>"I hear the word tracheostomy and I just worry. I worry what my family and my community will think."</p>

Theme	Sample Quotes
Parent psychosocial well-being	<p>"Looking at the crib last week was saddening because when you go through pregnancy you expect things to be okay after."</p> <p>"I cry a lot. It is hard, so hard."</p>
Financial burden	<p>"The financial concerns are also overwhelming, even with the benefits of health insurance."</p> <p>"I worry about money, but not because of caring."</p>
Medical fragility	<p>"It's not the role of caregiver that's frustrating, it is the fragility of the prognosis. I hold my breath all day long waiting for the next 'issue' positive or negative. It's completely unsettling."</p> <p>"Having a child who is medically fragile is one of the most difficult challenges of my life. It is a sacrifice that it absolutely worth it, but it is not a decision that should be taken lightly or without careful thought."</p>
Overwhelming medical care	<p>"Adding the trach just adds a new layer of responsibility and stress. Learning to care can be exhausting and overwhelming."</p> <p>"I wish I had known how difficult it is to find qualified nursing for the home, and I wish I had a better idea of how Medicaid works. Had I known that we wouldn't have night nurses due to a lack of availability I could have planned differently."</p>

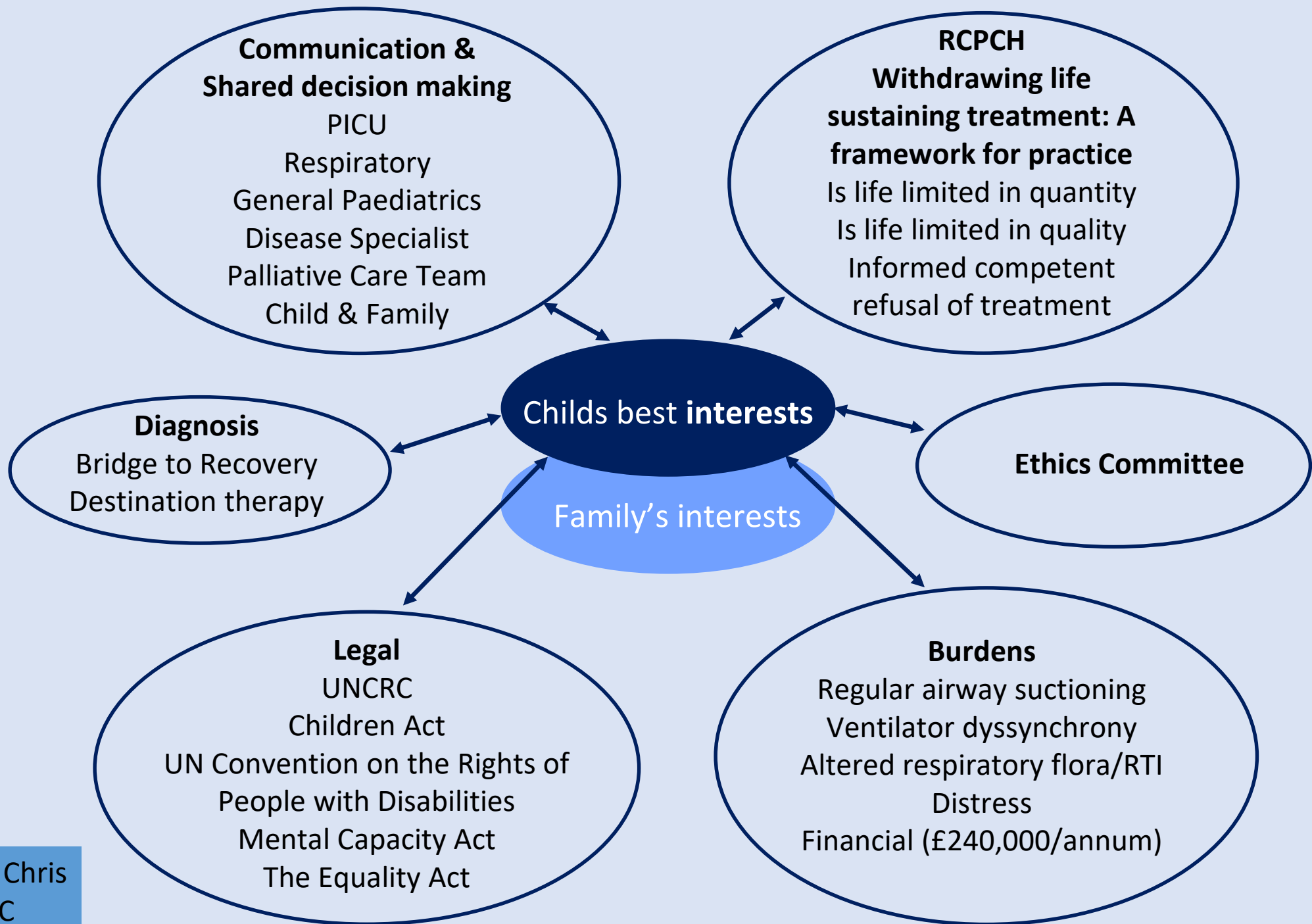
PEDIATRIC CRITICAL CARE MEDICINE

Themes:

- No Choice
- Uninformed
- Felt Pressured
- Overwhelming medical care
- Financial burden
- Regret timing

The UK Experience: QI review (2014) by the Patient Experience Network - some common themes...

- When we came out of intensive care we went into no-mans land
- I would have liked to have been able to make an informed decision (for tracheostomy).
- We were made to feel unwelcome on the ward
- Home is home – it needs to be safe – but it must be a home (medicalising the home!)
- I felt guilty because I was not doing things for my son (presence of carers)
- The local hospitals do not know how to deal with a Trachy and LTV.



Experiences from working in non NHS healthcare system.

- Saudi Arabia
- Rich economy
- No Home LTV service
- 8 year old child with neurodegenerative, lysosomal storage disorder - progressive intellectual and motor deterioration, seizures, and early death
- On NIV for 3 years – wheel chair bound; no home care system available- died in PICU
- Other cases trachy ventilated for varying times- all cared for in hospital until death.

Experiences from working in non NHS healthcare system.

- India
- Largely reliant on private health care
- Expensive world class hospitals with excellent medical staff
- No established system for home ventilation support services
- Now only the very rich able to take children requiring LTV home
- Employing full time trained ICU nursing staff at home

Anwarul Haque, Laila A. Ladak, Muhammad H. Hamid, Sadiq Mirza, Naveed R. Siddiqui, and Zulfiqar A. Bhutta, "A National Survey of Pediatric Intensive Care Units in Pakistan," Journal of Critical Care Medicine, vol. 2014, Article ID 842050, 4 pages, 2014. <https://doi.org/10.1155/2014/842050>.



16 PICUs : majority in Lahore; Karachi; Islamabad.
1 PICU bed/500,000

FIGURE 1: The locations of PICUs by province: each dot represents one PICU.

Ending with positive stories from the UK

- 2 year old girl with early onset Leigh's disease - poor respiratory effort – required LTV via tracheostomy.
- After 8 months PICU stay discharged home with a comprehensive care package.
- Parents delighted- child remains well at home.
- 10 week old boy with hypotonia and poor respiratory effort.
- Commenced on NIV and subsequently intubated and ventilated.
- Tracheostomy sited for LTV.
- Investigations confirmed a diagnosis of riboflavin transporter deficiency and treated with riboflavin.
- Discharged on LTV and home care in 6 months.

boy high-fives Prince Harry as youngster's bravery is honoured



Prince Harry, Duke of Sussex and Meghan, Duchess of Sussex meet four-year-old Mckenzie Brackley during the annual WellChild awards at Royal Lancaster Hotel on September 4, 2018.

He was unfazed as he met the Duke and Duchess of Sussex, better known as Prince Harry and Meghan Markle, and even managed a laugh and a joke with the Duke

Acknowledgements

- Respiratory team at RHSC : Lead role in initiating LTV decisions; training of parents and support PICU staff and child and family through the long process.
- LTV lead consultant - Dr Catherine McDougall
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- Well Child Respiratory Clinical nurse specialist Linda McCarthy