

GROWING TOGETHER

Patient centred strategies for the development of LTV care

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HEALTHCARE

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 **East of England
Paediatric
Critical Care**
Operational Delivery Network
Collaborative working to deliver high quality care to our children and their families

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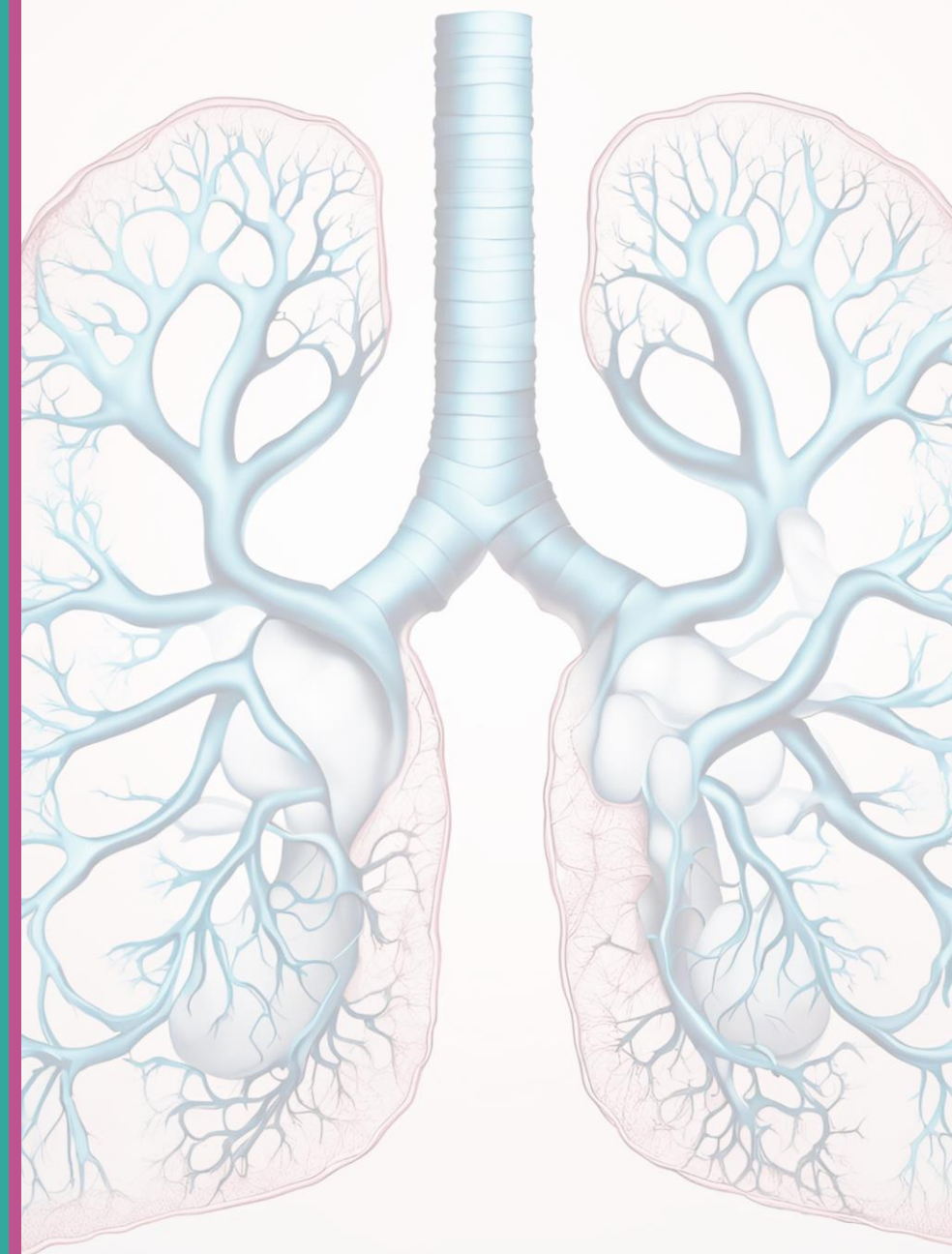
Pan Thames Paediatric LTV Programme

 North Thames Paediatric Network <small>Connecting paediatric services</small>	 South Thames Paediatric Network <small>Transforming Healthcare for Children and Young People</small>
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 **ODN** SiC
LTV
NORTH WEST PCC



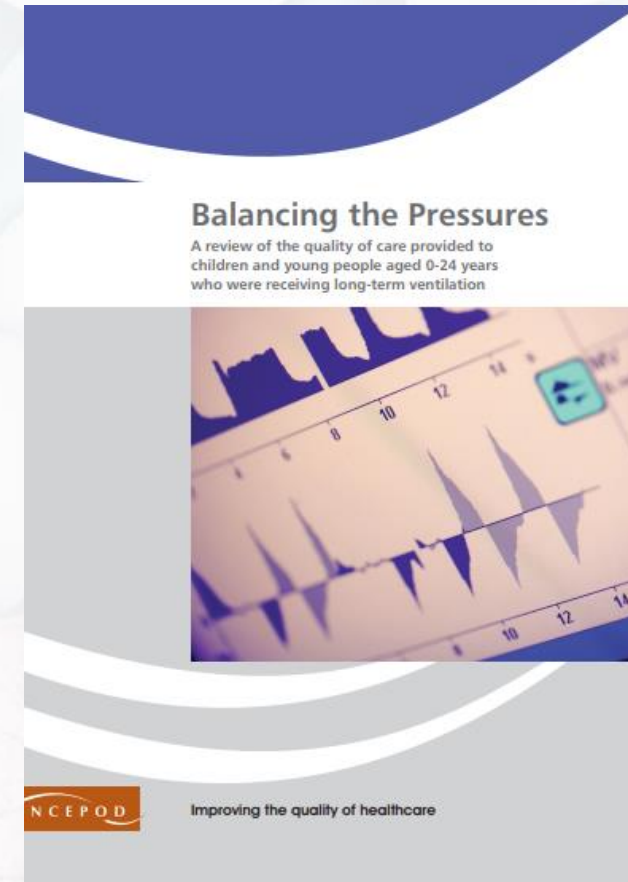
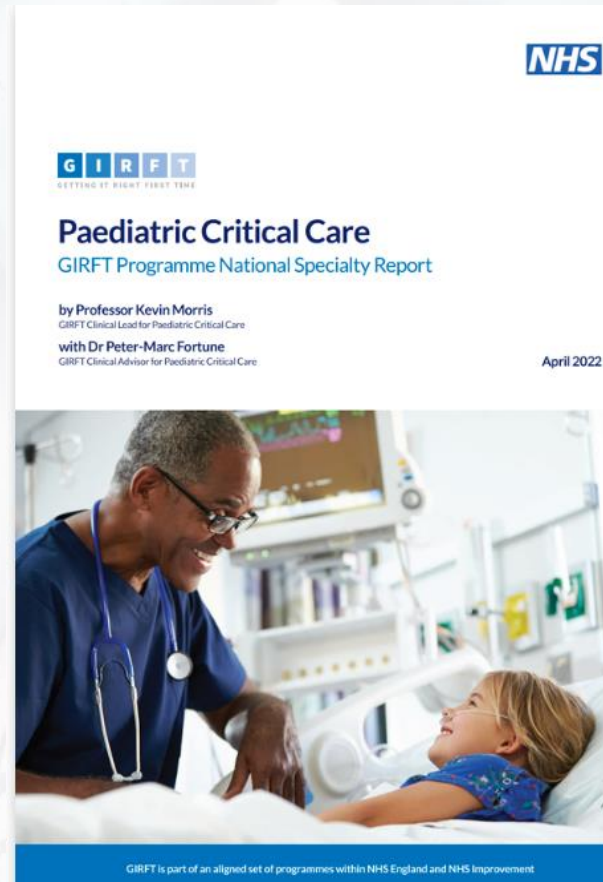
 **West Midlands
Children's Network**



LTV GIRFT update

**GIRFT – BEST PRACTICE PATHWAY - A CHILD ON LONG TERM NON-
INVASIVE VENTILATION WHO MAY REQUIRE ADMISSION TO
HOSPITAL**

Background



Background



Quality Standards

Services providing Long-Term Ventilation for
Children and Young People

Version 5

October 2022

GIRFT LTV: Scope & Aim

- Complex NIV only
- CYP established on LTV & discharged home
- **Focus:** pathway for readmission to hospital



Overview of key points

1. Strategies to reduce likelihood of hospital admission: Optimisation of home care
2. Early intervention [at home] during an acute respiratory deterioration
3. Interventions to minimise need for admission without respiratory deterioration
4. From home to hospital admission: Transfer, destination hospital and initial assessment area
5. Admission to in-patient unit

1. Strategies to reduce likelihood of hospital admission: Optimisation of home care



Parent & Carer
Competency Document
for Non Invasive
Ventilation (NIV) CYP



PPLTV
Paediatric Pan London Long Term Ventilation



2. Early intervention [at home] during an acute respiratory deterioration



3. Interventions to minimise need for admission without respiratory deterioration



4. From home to hospital admission: Transfer, destination hospital & initial assessment area



CATS PaNDR
PORT



Embrace NWTS



5. Admission to in-patient unit

0 to 11 months **NHS** 0 to 11 months

National Paediatric Early Warning System Observation and Escalation Chart

0-11 Months

Respiratory distress
Cyanosis
Apnoea
Tachypnoea
Retractions
Wheezing
Cough
Stridor
Other respiratory sounds

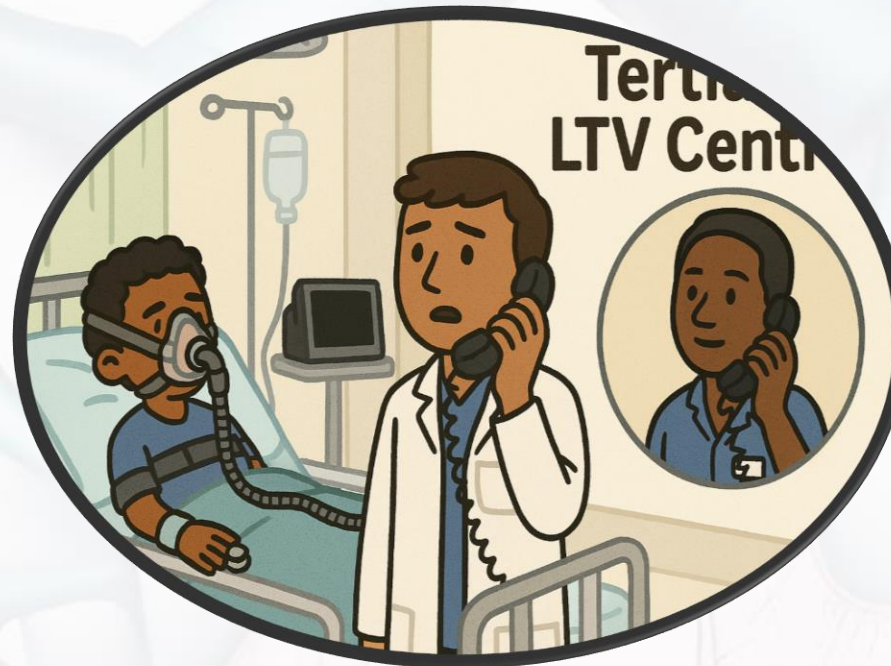
Central Nervous System
Altered consciousness
Seizures
Abnormal posturing
Abnormal reflexes
Abnormal vital signs

Circulation
Tachycardia
Bradycardia
Hypotension
Prolonged capillary refill time
Abnormal heart sounds
Abnormal peripheral pulses

Renal
Oliguria
Anuria
Abnormal urine colour
Abnormal urine odour

Metabolic
Hypoglycaemia
Hypocalcaemia
Hypomagnesaemia
Hypokalaemia
Hypophosphataemia
Abnormal acid-base balance

Other
Abnormal temperature
Abnormal blood pressure
Abnormal heart rate
Abnormal respiratory rate
Abnormal oxygen saturation
Abnormal pulse oximetry
Abnormal capillary refill time
Abnormal skin colour
Abnormal skin temperature
Abnormal skin moisture
Abnormal skin turgor
Abnormal skin elasticity
Abnormal skin sensation
Abnormal skin movement
Abnormal skin colour change
Abnormal skin temperature change
Abnormal skin moisture change
Abnormal skin turgor change
Abnormal skin elasticity change
Abnormal skin sensation change
Abnormal skin movement change
Abnormal skin colour change
Abnormal skin temperature change
Abnormal skin moisture change
Abnormal skin turgor change
Abnormal skin elasticity change
Abnormal skin sensation change
Abnormal skin movement change



5. Admission to in-patient unit

Hospital Admission Protocol (HAP)

What is the HAP?

The HAP is a formal agreement between the: Hospital, Parents, Community Children's Nursing Service, Commissioner and Care Agencies / Care package staff.

When a child, who has a continuing care package, is admitted to hospital the HAP allows:

- The child's care package to follow the child and remain in place
- For carers to act as 'expert parents', to ensure that the child's basic, often complex care is met.

The HAP protocol is **not** a substitute for medical acute care responsibilities / parental responsibilities. The HAP can be applied to all children with continuing care needs, not only those who receive LTV.

What are the benefits of implementing the HAP?

	With HAP	Without HAP
Child	<ul style="list-style-type: none">• Carers understand non-verbal cues & management plan• CYP more settled and better compliance, which can lead to a faster recovery• Improved patient experience	<ul style="list-style-type: none">• Distressed / doesn't settle easily with strangers• Poor compliance with treatment• Increased bed days → psychological impact• No advocate when parents not present
Parent	<ul style="list-style-type: none">• Reduced anxiety with known and familiar carer available• Parents able to recuperate during admission (exhaustion from looking after deteriorating child at home)	<ul style="list-style-type: none">• Other work/childcare commitments• Not able to leave bedside without relief• Adverse effect on family / mental health of parents/carers/siblings
Staff	<ul style="list-style-type: none">• CYP is always allocated a ward nurse for acute management• Eases pressure on ward staffing to provide 1-1 care for CYP 24 hours a day• Ward staff made aware of shift times and cover gaps between package shifts until the next carer arrives	<ul style="list-style-type: none">• Unfamiliar with CYP needs/non-verbal cues/equipment• May not have skills/knowledge to manage day to day care• Nursing burden: 1:1 care in cubicles, senior nurse allocation
Discharge	<ul style="list-style-type: none">• Smoother and faster discharge process as care staff remain working on the package• No gaps whilst awaiting staff availability to restart care on arrival home	<ul style="list-style-type: none">• Breakdown of care package, which can lead to a delayed discharge, waiting on care staff availability to restart care package• An increased LOS → increased risk of infection
Bed Status	<ul style="list-style-type: none">• Reduced LOS → Bed available for next patient	<ul style="list-style-type: none">• Bed being occupied when child is FFD

Implementation: Solutions and mitigations to challenges and perceived barriers of the HAP

- Funding: Paying two different staff members with different skill sets, which fulfil two different roles
- Current process: Without the HAP the CCT team are paid regardless, even when patient is admitted = double funding
- Bed Cost: If unable to safely deliver care locally, there is a cost burden of HDU transfer + HDU / PICU bed

- The HAP provides:
 - Clear roles and responsibilities
 - SLA and documentation in place

Contact the Pan Thames LTV Programme for more information about the Hospital Admission Protocol



Long Term Ventilation in Children and Young People Clinical Guideline

Thames Valley and Wessex
CHILDREN AND YOUNG PEOPLE
Operational Delivery Network

North Thames
Paediatric Network
Connecting paediatric services

South Thames
Paediatric Network
Specialist paediatric care for Children and Young People

East of England
Paediatric Critical Care
Specialist paediatric care for Children and Young People

Pan Thames Paediatric LTV Programme

North Thames Paediatric Network

South Thames Paediatric Network

LTV HUB

1st September 2020 - Information was correct at time of printing. For review: September 2025. Some equipment and policies after signing between LTV centres, please contact your local LTV Centre for more information and ensure that you are working to that policy.

Access more Resources, Videos, e-learning and Competency Documents on our Website: <https://lts.services/>

Access Complex Discharge Guidance and Tools developed in collaboration with Westlincs <https://www.westlincs.org.uk/lts-articles-for-complex-discharge>

SCAN ME

LTV Guideline

MEDICAL EQUIPMENT USER GUIDES AND TROUBLESHOOTING

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SCAN ME

SCAN ME

SCAN ME

SCAN ME

Astral 150

Trilogy 100

Trilogy Evo

Nippy Junior +

Nippy A4+

SCAN ME

SCAN ME

SCAN ME

SCAN ME

SCAN ME

AirSense 10

Stellar 100 & 150

CIRCUIT SET UP

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SCAN ME

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SCAN ME

NIV

Trache LTV

LTV E-Learning

EDUCATION RESOURCES - VIDEOS

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Respiratory Assessment

Respiratory Action Plan (RAP)

Mask fitting for NIIV

Pressure sores & NIIV

NIIV Equipment troubleshooting

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Further information: <https://lts.services/>

Or contact the Team: Manual.ltv@lts.org.uk

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Suctioning a tracheostomy

Partially blocked Tracheostomy

Blocked Tracheostomy

SLS Tracheostomy

LTV Safety Checks Video

Overview of key points


6. The LTV child requiring admission for surgery or procedures: Surgery key considerations
7. Advanced Care Planning
8. Equipment
9. Commissioning
10. Coding and data capture

6. The LTV child requiring admission for surgery or procedures: Surgery key considerations



7. Advanced Care Planning

Name: _____ DOB: _____ NHS No: _____

 Child and Young Person's Advance Care Plan

ID photo _____ QR code _____

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES
Plans can begin antenatally (using ante-natal version of this document) and are suitable for infants, children and young people

Name (baby, infant, child or young person):	EDD (if relevant):
Known as (if different):	DOB:
Address including postcode:	
NHS no:	Gender (optional):

ALLERGIES:

For Child/Young Person or Carers' Use – Who to call in emergency (eg 999 or 111, or Hospice, etc)

In emergency call:

Other situations:

See also Emergency Contacts on last page

This document is in accordance with NICE guideline NG61 and is a tool for discussing care preferences and communicating wishes. It is intended to enable clinicians and families to make good decisions together.

Not every page/section needs to be completed.

Date of Plan/last review: _____



Pan Thames Paediatric LTV Programme

Ethical Framework for Decision Making in Long-Term Ventilation

Content

Introduction	1
Regional Paediatric Bioethics Group	2
LTV Operational Pathway	3
LTV Ethical Principles Framework	4
1 – Principles to guide decision making in children subject to Long Term Ventilation. Checklist proforma to support MDT meetings	4
2 – MDT members list for clinical best interest meeting	6

Introduction

Long Term Ventilation (LTV) is defined as requirement for ventilation via a tracheostomy or non-invasive interface for at least 16 continuous hours per day. In this way we have decided to necessarily limit this consideration to those children most likely to not survive without this support. (Other children e.g. those expected to deteriorate and likely to eventually require 16 hours of LTV can be discussed using the framework if helpful but are not the primary group)

NICE National Institute for Health and Care Excellence Search NICE...

Guidance Standards and indicators Life sciences British National Formulary (BNF) British National Formulary for Children (BNFC) Clinical Knowledge Summaries (CKS) About

Home > NICE Guidance > Health and social care delivery > Children's social care

End of life care for infants, children and young people

Quality standard | QS160 | Published: 12 September 2017

Quality standard Tools and resources History

Download (PDF) Overview

Overview

This quality standard covers end of life care for infants, children and young people (from birth to 18 years) who have a life-limiting condition. Life-limiting conditions are those that are expected to result in an early death for the person. It also covers support for family members and carers. It describes high-quality care in priority areas for improvement

8. Equipment

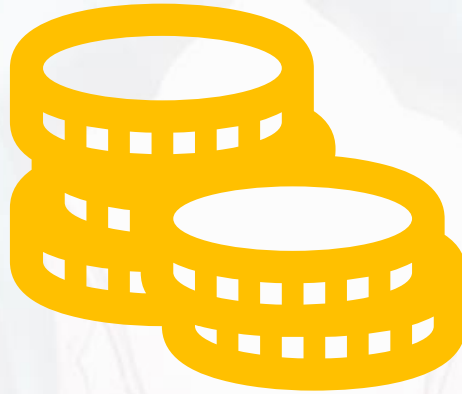


NIV Interfaces Guide and optimal mask fit for Long Term Ventilation

Safety and Fitting Guidance

Interface Type	Good Interface fit
Vented Interface <ul style="list-style-type: none"> Exhalation port/ leak (an intentional leak) is built into the interface – this allows the CYP to safely expire in the single limb circuit Most CYP on ventilators at home have vented interfaces <ul style="list-style-type: none"> Exhalation port/ leak - Feel for expiratory air flow to ensure leak is patent and working Anti asphyxiation valve reduces risk of rebreathing of CO₂ if ventilation stopped and the mask still attached to CYP (e.g. power failure) 	Nasal Pillow <ul style="list-style-type: none"> Sits inside nostrils creating a seal around the inside of the nostrils Ensure that the inner walls of one or both pillows are not out of shape, compressed or collapsed
Non-vented Interface <ul style="list-style-type: none"> There is no exhalation port/ leak Often used for acute NIV in a PICU/ HDU setting and not in LTV Should not be used in a single limb circuit due to the lack of an exhalation port/ leak- requires a dual limb circuit or additional exhalation port/ leak (ensure advice is sought from the CYP respiratory centre) 	Nasal Mask <ul style="list-style-type: none"> Sits on top of the bridge of the nose Ensure mask not occluding nostrils Ensure top lip is not in the nasal mask Ensure there is no leak into the eyes as this can cause dryness and discomfort
Fitting Guidance <ul style="list-style-type: none"> Fit mask first, with no tubing attached- ensure head gear straps are not too tight or loose. Use a two finger technique when checking head strap tension Once mask fitted, connect tubing and then start ventilation Check for leaks anywhere around the interface by feeling with your hands for air escaping. Exhalation port/ leak - Feel for expiratory air flow to ensure leak is patent and working 	Full Face Mask <ul style="list-style-type: none"> Sits on top of the bridge of the nose Sits on the chin, under the bottom lip Ensure eyes not covered/ no leak into eyes
	Oral-Nasal Mask <ul style="list-style-type: none"> Nasal pillows sit in nostrils Oral mask section sits on the chin, under the bottom lip
	Total Face Mask <ul style="list-style-type: none"> Sits on the forehead Comfortably covers eyes, nose & mouth Sits on the chin, under the bottom lip

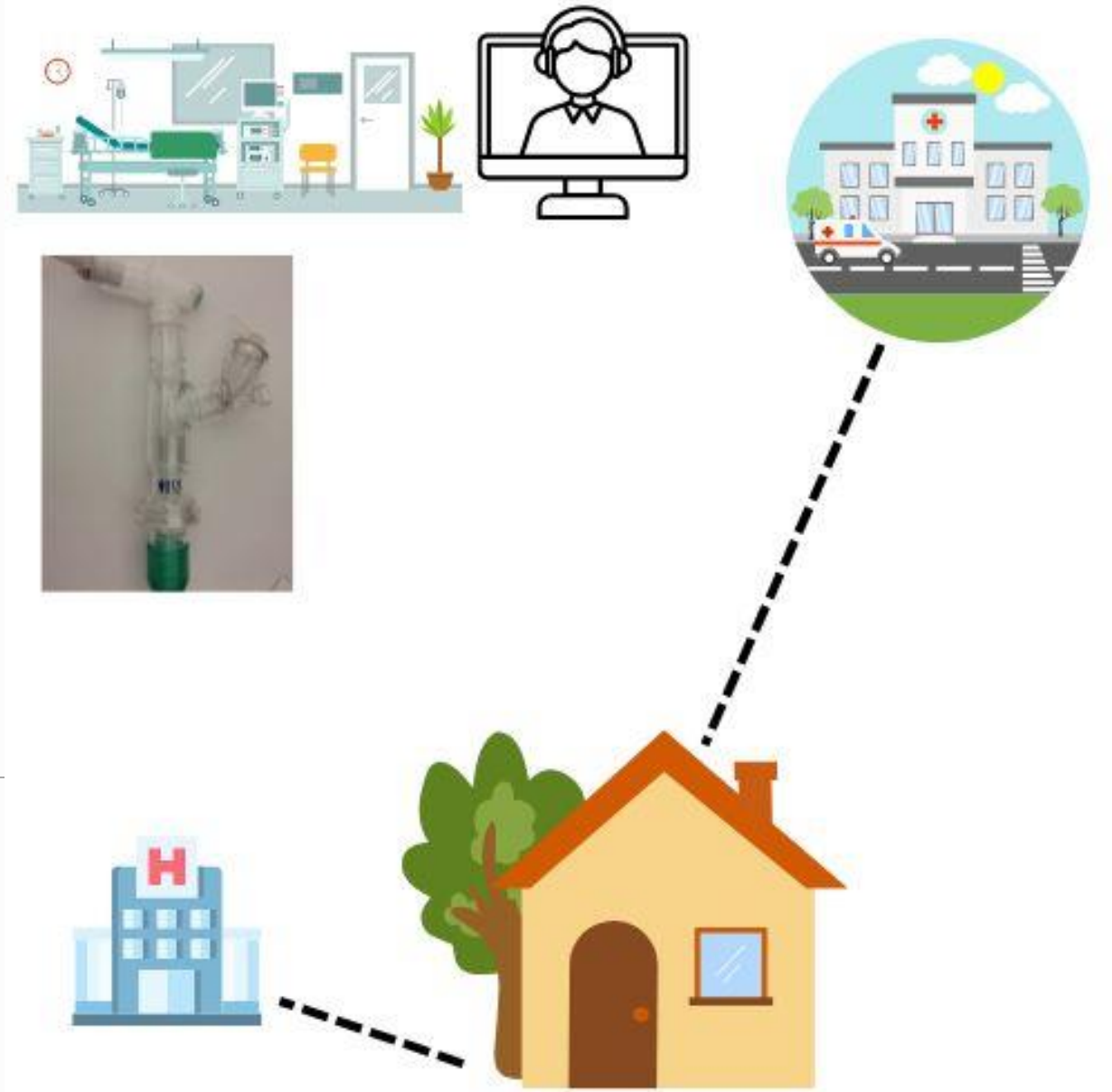
9. Commissioning



10. Coding and Data Capture



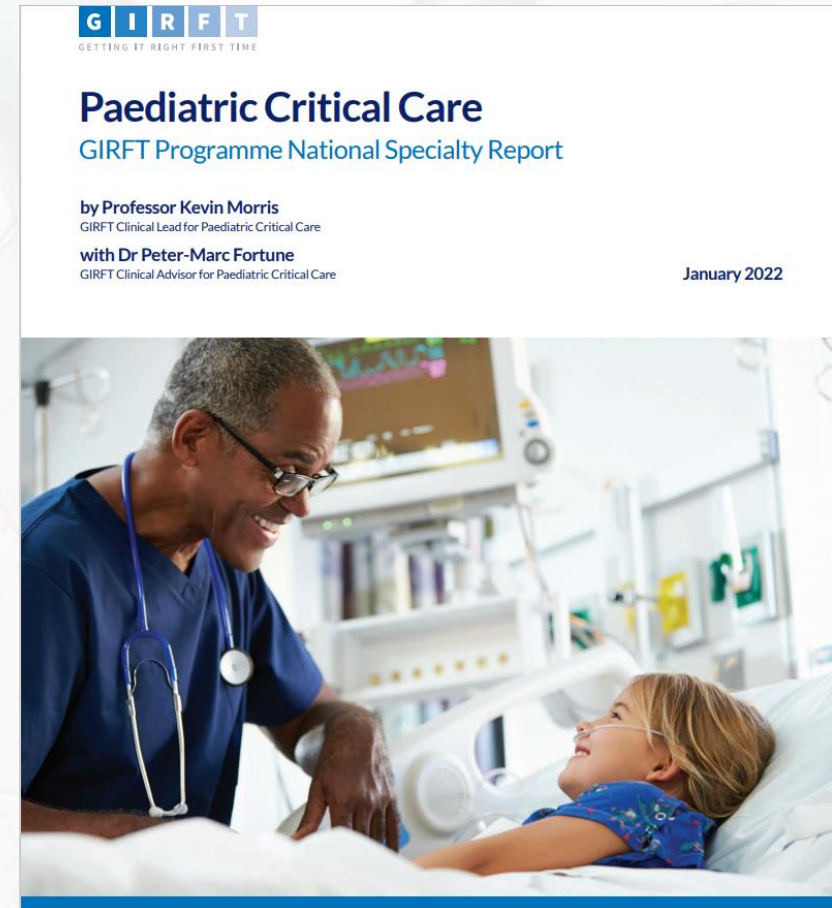
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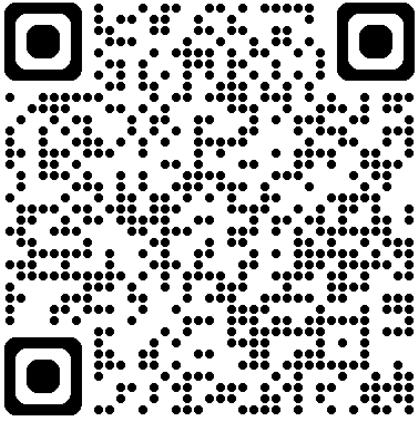
Current Stage

Non-invasive ventilation section

- Final draft circulated to GIRFT working group
- NHS GIRFT team formatting
- Key stakeholder peer review
- Circulate
- Finalisation
- Publish –winter 2025?



<https://ltv.services/>



Pan Thames Paediatric LTV Programme



**North Thames
Paediatric Network**
Connecting paediatric services



**South Thames
Paediatric Network**
Transforming Healthcare for
Children and Young People

Emilie Maughan
Senior Project Manager

Emilie.Maughan@gstt.nhs.uk

Selina Wong
LTV Skills and Education Implementation
Lead (NT region)

References & further reading

- GIRFT, NHSE & NHS Improvement (2022) *Paediatric Critical Care National Speciality Report* Available at: [Paediatric Critical Care - Getting It Right First Time - GIRFT](#)
- MCLTVN (2022) *Quality Standards Services Providing Long Term Ventilation for Children and Young People* Available at: [Midlands Children's Long Term Ventilation Network \(MCLTVN\) - Partners in Paediatrics](#)
- NCEPOD (2020) *Long Term Ventilation: Balancing the Pressures* Available at: [NCEPOD - Long Term Ventilation: \(2020\)](#)
- NHSE & NHS Improvement (2019) *Paediatric Critical Care and Surgery in Children review* Available at: [Paediatric critical care and surgery in children review: Summary report](#)