Pan Thames Paediatric LTV Programme

North Thames Paediatric Network
Connecting paediatric services

South Thames Paediatric Network
Transforming Healthcare for Children and Young People

Pan-Thames Paediatric Long-Term Ventilation (LTV) Programme

Annual report 2025-26

https://ltv.services/

NHS

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A message from the Programme Lead

This Annual Report sets out the impact of the Pan Thames Paediatric Long-Term Ventilation (LTV) Programme at a time of rising demand and increasing system pressure. Covering London, Kent, Surrey, Sussex and neighbouring Trusts in the East of England, the programme provides critical regional coordination to support safe, consistent LTV care and protect specialist Pediatric Intensive Care Unit (PICU) and tertiary capacity.

Babies, children and young people on LTV are among the most complex patients in the system. Delays and pressure are frequently driven by skills gaps, pathway fragmentation and non-clinical barriers, particularly housing, rather than clinical need alone. The programme addresses these challenges by reducing unwarranted variation, supporting timely discharge and enabling care to be delivered safely closer to home.

This year has focused on scaling delivery: embedding LTV skills across hospital and community settings, sustaining housing and welfare support to address delayed discharge, improving system-wide data visibility, and progressing a more coordinated approach to high-cost LTV equipment. Together, these actions are improving patient flow, safety and value for the system.

As LTV pathways increasingly intersect with neonatal care, PICU, Emergency Departments (EDs) and community services, closer alignment with Neonatal Operational Delivery Networks (ODNs) and the South and North Thames Paediatric Networks is essential. This report highlights the progress made, current pressures, and the priorities for commissioners and clinical teams working together to strengthen LTV pathways across the region.

I would like to thank our clinical leads - Dr Richard Chavasse, Dr Elaine Chan, Dr Seema Sukhani and Dr Reshmy Nair - whose leadership has been central to the programme's development and impact. As the programme evolves, we are pleased to welcome Dr Reena Bhatt as incoming Pan Thames Clinical Lead, building on this strong foundation.

I also want to recognise the commitment of the programme team and the clinical teams delivering care day-to-day. Babies, children and young people on LTV sit at the heart of our work, and as ICBs shape local commissioning arrangements, we look forward to continuing our shared efforts to strengthen paediatric LTV pathways and deliver a more connected, resilient system for families across the region.

Miriam Rosen-Cabib
Programme Manager

Understanding Long-Term Ventilation (LTV)

What is LTV?

Long-term ventilation (LTV) refers to various types of respiratory support provided every day for a period of at least three months. 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 (NCEPOD, 2020).

LTV is not a diagnosis. Babies, children and young people (BCYP) receiving LTV have a wide range of underlying conditions, including neuromuscular disorders, airway abnormalities, severe chronic lung disease of prematurity, neurological conditions and complex multi-system disorders. As a result, BCYP on LTV represent a clinically diverse population with very different trajectories, levels of dependency and care needs.

Why regional coordination matters

The national picture

Pressures on PICU and HDU capacity is often driven by system factors - not clinical instability alone

National reviews — National Confidential Enquiry into Patient Outcome and Death (NCEPOD) Balancing the Pressures (2020), Getting It Right First Time (GIRFT) Paediatric Critical Care (2022), and the Children's Commissioner's report on children waiting to leave hospital (2026) — consistently show that BCYP on LTV:

- Experience avoidable admissions and prolonged stays
- Apply pressure on PICU and High Dependency Unit (HDU) capacity
- Receive variation in care delivery

Critically, these pressures are often driven not by clinical instability alone, but by system factors, including:

- Fragmented pathways
- Variable workforce capability outside PICU settings
- Limited step-down options
- Equipment delays
- Non-clinical barriers such as housing and social care

A complex, cross - system pathway

LTV pathways do not sit within single organisations or footprints.

BCYP on LTV move between:

- Neonatal intensive care units (NICU)
- PICU (paediatric intensive care Level 3 units) and HDU (paediatric Level 2 intensive care beds)
- District general hospitals (DGH)
- Community services and hospices
- Home and school

This care often spans multiple ICB boundaries.
Without regional coordination, this complexity leads to:

- Duplication and inefficiency
- Unnecessary escalation to paediatric intensive care Level 3
- Inequitable experiences for families

Pan Thames approach

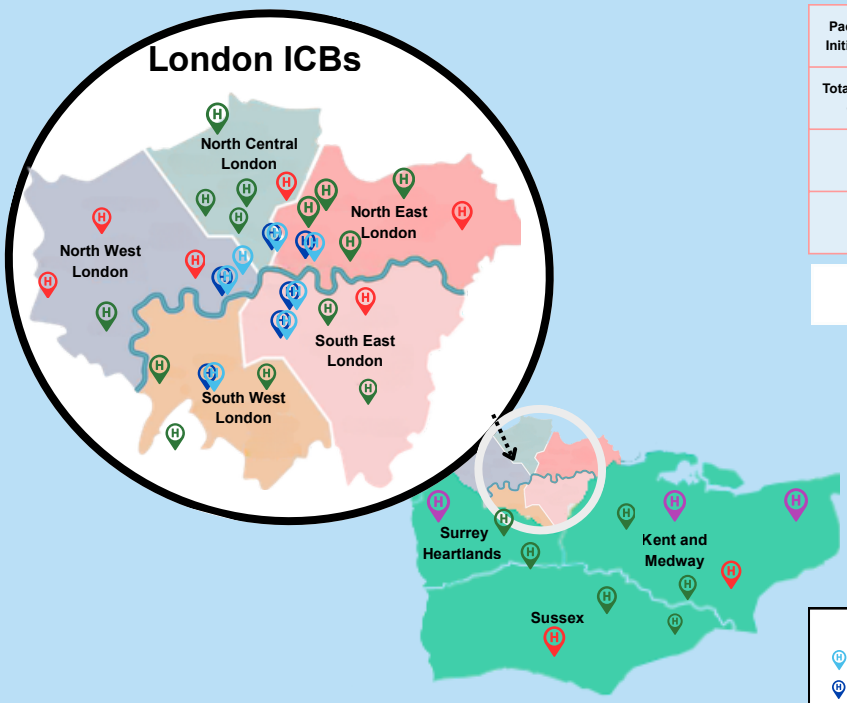
Coordinated care at scale

The Pan Thames Paediatric LTV Programme provides regional coordination across the North and South Thames Paediatric Networks, working with providers and ICBs to:

- Support shared pathways and consistent standards
- Enable joint problem-solving across system boundaries
- Deliver care in the right place, at the right time

This directly aligns with GIRFT Paediatric Critical Care (2022) recommendations and the Children's Commissioner's call to reduce avoidable hospital stays, while protecting high-cost PICU and HDU capacity.

2025-26 Geography



South East England ICBs in STPN

Paediatric LTV Initiating centre	A	B	C	D	E	F
Total patients on caseload	208	351	158	69	219	50
NIV	195	309	141	60	182	47
TrLTV	13	42	17	9	37	<5

Number of babies, children and young people on LTV (2025 self-reported caseload data)

KEY

- Paediatric Intensive Care (PIC) Level 3 Units
- Centres that initiate paediatric LTV
- Stand-alone PCC Level 2 Commissioned Beds (SDF*)
- Stand-alone PCC Level 2 Commissioned Beds (Newly Established through SDF*)
- PIC Level 1 Units

*SDF = Service Development Funding

**** North West London and North Central London ICB's merged to form West and North London ICB on 1st April 2026**

North West London **

- Royal Brompton Hospital *(LTV centre and inpatient services (including PICU level 3 will be temporarily moving to the Evelina from 11th May 2026 - referral pathways will remain unchanged).*
- St Mary's Hospital
- Northwick Park Hospital
- Hillingdon Hospital
- Chelsea and Westminster Hospital
- West Middlesex University Hospital

North Central London **

- Great Ormond Street Hospital for Children
- Whittington Hospital
- North Middlesex University Hospital
- Barnet Hospital
- Royal Free Hospital University College Hospital

North East London

- Royal London Hospital
- Newham University Hospital
- Whipps Cross University Hospital
- Queen's Hospital
- Homerton University Hospital
- Princess Alexandra Hospital

South West London

- St George's Hospital
- Croydon University Hospital
- Epsom General Hospital
- Kingston Hospital
- St Helier Hospital

South East London

- Evelina London Children's Hospital
- King's College Hospital
- Princess Royal University Hospital
- University Hospital Lewisham
- Queen Elizabeth Hospital (Woolwich)

Kent and Medway

- William Harvey Hospital
- Queen Elizabeth The Queen Mother Hospital
- Maidstone and Tunbridge Wells NHS Trust
- Darent Valley Hospital
- Medway Maritime Hospital

Surrey Heartlands

- St Peter's Hospital
- Easy Surrey Hospital
- Royal County Hospital

Sussex

- Royal Alexander Children's Hospital
- Conquest Hospital

East of England

- Luton & Dunstable University Hospital
- Lister Hospital
- Basildon University Hospital
- Broomfield Hospital
- Princess Alexandra Hospital
- Watford General Hospital
- Southend University Hospital

Paediatric LTV referral routes and pathways have evolved over time in response to local services and specialist expertise and continue to change as ICBs and provider configurations develop. The LTV system should therefore be understood as dynamic.

The Pan Thames Paediatric LTV Programme supports clarity and alignment across this complexity, working with ICBs and providers to improve consistency, reduce unwarranted variation and maintain clear, up to date and geographically accessible pathways that supports care closer to home for babies, children and young people.

Model of Care

BCYP enter LTV pathways at different points - some from NICU (Neonatal intensive care unit) or PICU (Paediatric intensive care unit) where long-term respiratory support is identified early after birth, others later in childhood following acute illness or progression of an underlying condition.

Over time, children move through a tiered system of care - Paediatric Intensive Care (PIC) Level 3 units, PIC Level 2, PIC Level 1 beds in DGHs - with escalation or step-down determined by clinical stability and phase of care.

Across the Pan Thames region, PIC Level 3 units are: St Mary's Hospital, Great Ormond Street Hospital, Evelina London Children's Hospital, Royal Brompton Hospital, the Royal London Hospital, St George's Hospital and King's College Hospital.

Initiation of paediatric LTV is provided at all these centres except St Mary's.

The ongoing management of patients on LTV is supported by a wider network of stand-alone DGH-based PIC Level 2 and Level 1 paediatric beds which contribute to care closer to home (please refer to the map above for details of hospitals commissioned to provide stand-alone PIC Level 2 and Level 1 care).

Access to step-down PIC Level 2 care for BCYP on LTV varies geographically, reflecting differences in local service configuration across ICBs.

Transitional care units, which have been shown to reduce length of stay in PICU, are currently available only in a small number of tertiary centres (Great Ormond Street hospital and Evelina London Children hospital), while stand-alone PIC Level 2 beds in District General Hospitals play an increasingly important role in enabling care closer to home. However, not all areas have commissioned and established Level 2 capacity, meaning that opportunities for timely step-down and local care are not uniformly available (refer to the map above for details of hospitals commissioned to provide stand-alone PIC Level 2 care).

This variation has implications for patient flow, length of stay in tertiary services and equity of access to care closer to home as services continue to develop.

Programme Remit and Governance

The Pan Thames Paediatric LTV Programme operates across the care pathway between tertiary, DGHs and local care settings. It does not deliver direct clinical care; instead, it provides a regional, system-level function focused on acute flow.

The programme's primary aim is to reduce the time BCYP on LTV spend in tertiary and critical care beds, once this is no longer clinically required. It does this by supporting effective use of transitional and PIC Level 2 capacity, enabling timely step-down and discharge, and improving coordination between services.

The programme works alongside established neonatal, paediatric critical care and transport pathways including the South Thames Retrieval Service (STRS) and the Children's Acute Transport Service (CATS), promoting consistent understanding of escalation and step-down routes and reducing unwarranted variation across the system. Local clinical responsibility remains unchanged.

The programme was established by NHSE and is now jointly commissioned with London ICBs and hosted by Guy's and St Thomas' NHS Foundation Trust.

It is jointly managed through the South Thames Paediatric Network (STPN) and the North Thames Paediatric Network (NTPN), providing a region-wide function aligned with wider paediatric critical care priorities across North and South Thames.

Our Team

The Pan Thames Paediatric Long-Term Ventilation Programme is delivered by a dedicated multidisciplinary team combining clinical leadership with programme management, nursing, therapy, education, housing, and business support expertise.

Below the 2025-26 team structure:

Dr Richard Chavasse
Tertiary centres clinical lead for South Thames until 30th June 2026

Dr Elaine Chan
Tertiary centres clinical lead for North Thames until 30th June 2026

Dr Seema Sukhani
DGHs`Co-clinical lead for North Thames until 31st March 2026

Reshmy Nair
DGHs`Co-clinical lead for North Thames until 31st March 2026

Miriam Rosen-Cabib
Programme Manager

Laura Koehli
Senior Project Manager

Tanya O'Driscoll
Interim NTPN Nurse Manager, Network Lead Nurse Surgery in Children ODN (North Thames Paediatric Network)

Emilie Maughan
Senior Project Manager currently on career break-leave

Melanie Amos
Pan Thames LTV Physiotherapy lead

Emma Whitcombe
LTV Skills Implementation Lead

Alice Francis
LTV Skills Implementation Lead

Jade Rand
LTV Skills Implementation Lead

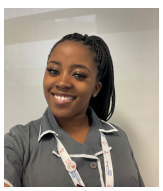
Selina Wong
LTV Skills Implementation Lead until Nov 25

Emma Ashrafi
Social Welfare and Housing Lead

Annabel Coyle-Stewart
Project and Engagement officer

Manal Naji
Business Support Manager

Dr Reena Bhatt



Shadae Kamese

Thank you to our clinical leads – Dr Richard Chavasse and Dr Elaine Chan, who will complete their tenure in June 2026, and Dr Seema Sukhani, Dr Reshmy Nair, as well as our Skills Implementation Lead, Selina Wong, who have already completed their time with the Programme. We are very grateful for their leadership and significant contribution during their time with the Programme, which has been central to its development and impact. We are grateful for their leadership, commitment, and enthusiasm to ensure improved LTV pathways for BCYP during their time with the Programme, which has been central to its development and impact.

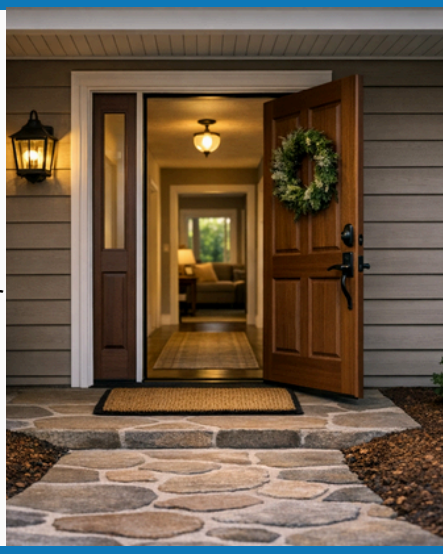
We are pleased to welcome Dr Reena Bhatt as incoming Pan Thames Clinical Lead, and Shadae Kamese as incoming Skills Implementation Lead, building on this strong foundation.

2025-26 Priorities

The 2025-26 programme's priorities were informed by national guidance, regional data, audit findings and system partners, and selected to maximise impact and value for money

Care Closer to Home

Safe care closer to home depends on a skilled workforce and clear pathways. Despite progress in stand-alone PIC Level 2 services across the region, variation in capacity, confidence, capability and pathway clarity continues to influence where care is most appropriately delivered. In 2025–26, the Programme focused on targeted education, training and pathway development to strengthen frontline capability across acute and DGH settings, supporting earlier step-down and safer discharge.



The following pages set out:

- LTV skills implementation and education across the region
- Pathway development supporting discharge and step-down

Smarter use of Resources

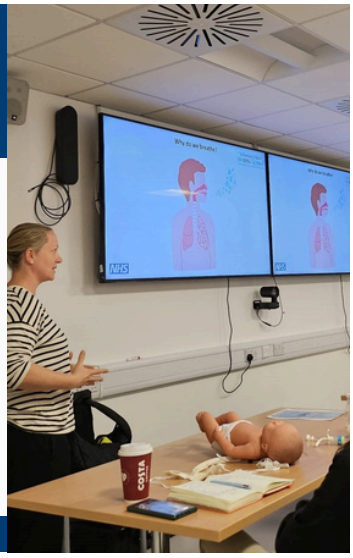
BCYP on LTV require significant system investment. The Programme focused on regional coordination, reducing duplication, releasing clinical capacity and improving value for money while maintaining quality and safety.

The following pages cover:

- Productivity and value for money
- Regional data and equipment approaches

Reducing Unwarranted Variation

Variation in access to care and decision-making continues to drive inequity and delays. The Programme focused on shared standards, strengthened governance and workforce audit to support greater consistency across Pan Thames.



The following pages cover:

- Shared standards and best practice
- Workforce audit and system governance

2025–26 Impact

What we delivered

During 2025–26, the Programme embedded a number of high-impact interventions across the Pan Thames region:

- Strengthening frontline capability through LTV skills implementation across acute, DGHs and community settings, supporting safer step-down and earlier discharge
- Reducing non-clinical delays via dedicated housing and welfare support, addressing one of the most persistent causes of delayed discharge through cross-system working
- Improving commissioning intelligence by strengthening regional data and demand modelling in the absence of a national LTV dataset
- Smarter use of high-cost resources through shared education, digital infrastructure and progress towards coordinated equipment approaches

The pages that follow report in detail on delivery and impact against each priority.

Care closer to home: LTV education and skills

Aims

The Pan Thames Paediatric LTV Programme aims to enable BCYP requiring LTV to be cared for as close to home as possible, where clinically appropriate. This is facilitated by improving the confidence and competence of healthcare professionals across acute and community settings to safely manage LTV outside tertiary centres, in line with national guidance.

Expected benefits

- Increased capability within DGHs, Level 2 units, and Emergency Departments to manage BCYP on LTV safely
- Timelier step-down from tertiary centres and improved acceptance of appropriate local admissions
- Reduced reliance on critical care for clinically stable children
- Safer, more consistent care through standardised education and trusted resources
- A more confident workforce supported by flexible, accessible training models

Key Successes 2025/26

01

Comprehensive & flexible regional education delivery

02

Digital learning and trusted resources

03

Demonstrable improvement in confidence and capability

04

Contributions across national and regional projects

Looking Ahead

In 2026/27, the programme will build on this progress by further strengthening PIC Level 2 and ED service capability, expanding community-focused education, embedding core LTV resources into scenario-based training, and working closely with ODN, retrieval and tertiary partners to maximise reach and sustainability. Together, this work continues to support safer care, improved patient flow and the delivery of high-quality LTV care as close to home as possible.

A Closer look at Key Successes 2025-26

01

Comprehensive regional education delivery

Over the past year, education delivery has focused on building confidence and capability in LTV care across hospital and community teams. To widen reach and maximise engagement, a broad, blended education offer has been developed, including guidance, digital and virtual resources, peer support, and face-to-face learning. This mixed approach ensures relevance across diverse professional groups and care settings.

The Skills Implementation Leads delivered education to the clinical areas most likely to encounter BCYP on LTV, including DGHs with stand-alone PIC Level 2 beds (established and newly commissioned), inpatient wards, Paediatric Assessment Units (PAU), Emergency Departments (ED), community nursing teams, hospices and London Ambulance Service. Across the Pan Thames region, we delivered 22 Full Study Days.

All Level 2 District General Hospitals engaged with Pan Thames LTV education during the year, either through direct delivery, co-delivery or established train-the-trainer models. Education support directly contributed to the successful opening of LTV-capable Level 2 beds in a newly commissioned DGH ahead of winter 2026 (refer to Appendix A for individual hospitals information and data).

Ongoing staffing pressures limited release of staff for training, with many trusts able to release only 2–3% of staff per rota, resulting in the cancellation of some planned study days. In response, following a targeted learning needs analysis and site visits, an expanded programme of shorter education sessions were implemented to better understand local pathways, strengthen relationships, and inform future education planning. This included the successful launch of monthly Vent & Learn sessions and a significant expansion of short-format education, increasing delivery from 7 sessions in 2024/25 to 26 in 2025/26.

Jade Rand, Emma Whitcombe, Alice Francis, Skills Implementation Leads

"Very well conducted and relevant topics - nurse led but doctors dont experience the machines or tubing as much so this was very good hands on experience for troubleshooting"

"Very interactive and hands on to practice in tracheostomy and SIM was great"

Learners feedback from study days

02

Digital learning and trusted resources

The programme continued to strengthen it's training offer through digital education and point-of-care resources.

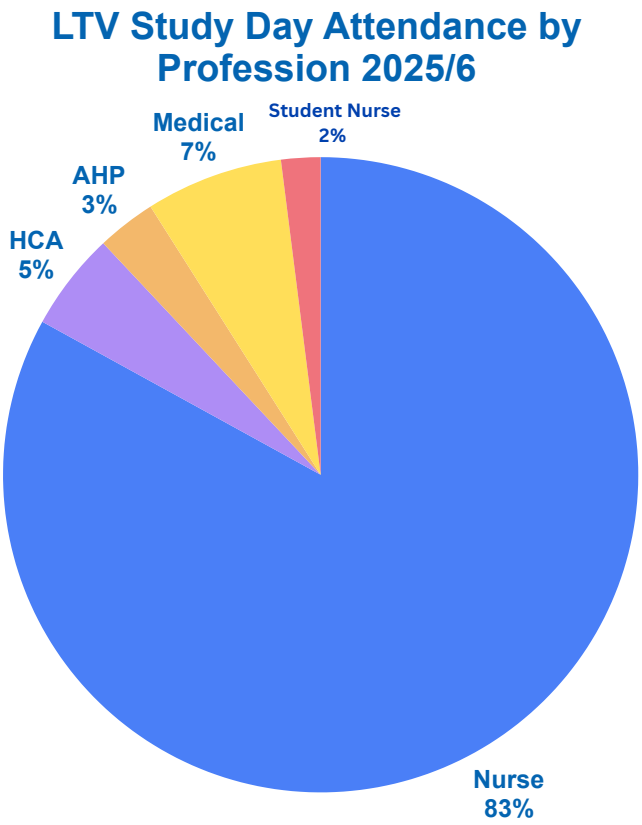
The LTV eLearning module, launched in December 2024, achieved 260 completions by year-end, with sustained uptake for a non-mandatory module and 99% learner recommendation. A new Introduction to Paediatric Tracheostomy eLearning module was launched in March 2026, providing a standardised foundation for safe care across both networks. Engagement with LTV resources remained strong, with 817 clicks to our LTV Clinical Guideline, and use of the LTV Hub poster increasing by 84% year-on-year, reflecting growing reliance on accessible, trusted guidance. Confidence data shows intended learning outcomes were met, with LTV resource awareness rising from 41% to 98%.

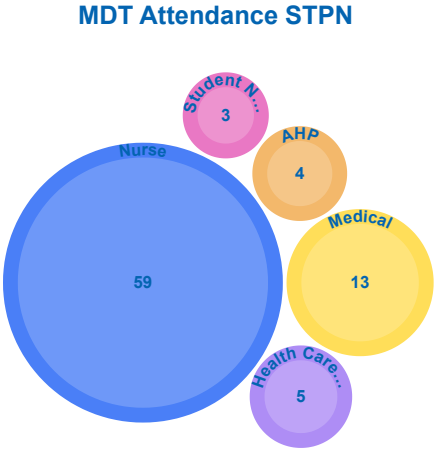
03

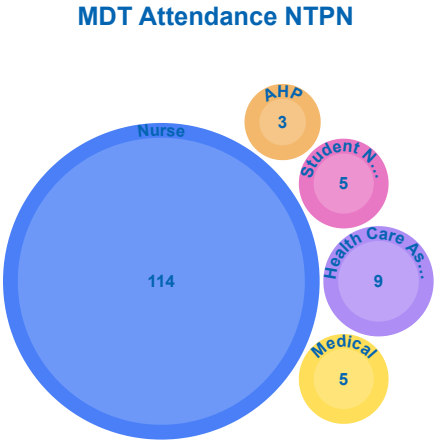
Demonstrable improvement in confidence and capability

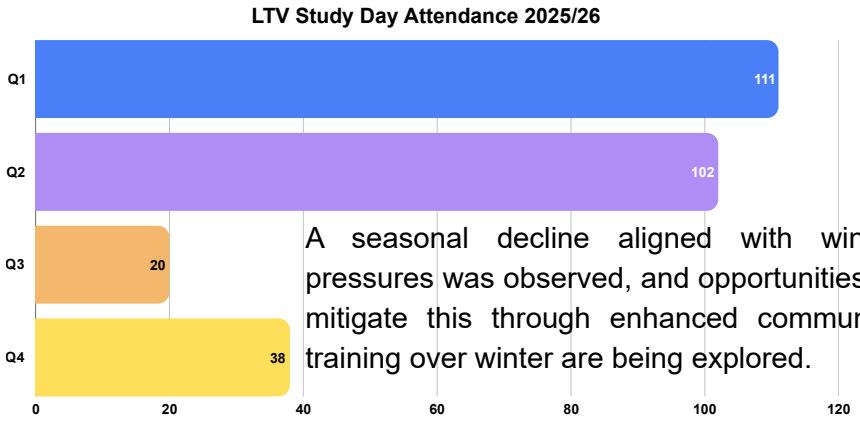
Education reached multidisciplinary teams across nursing, medical and allied health professional groups, strengthening shared understanding and consistency of care. Evaluation from full LTV study days demonstrated significant improvements in confidence:

- Confidence in assessing a child on LTV increased from 19% pre-course to 89% post-course
- Confidence in troubleshooting ventilation increased from 4% to 83%
- Awareness of key LTV resources increased from 41% to 98%









A seasonal decline aligned with winter pressures was observed, and opportunities to mitigate this through enhanced community training over winter are being explored.

4%
Work in Paediatric Assessment Units (Q3 & Q4)

14%
Work in Emergency Department (Q3 & Q4)

04

Wider system contribution

Alongside delivery, our Skills Implementation Leads provided clinical and educational input into regional and national initiatives, including GIRFT best practice guidance, continuing care standards and Pan Thames operational governance, ensuring alignment between education, service development and national policy.

For any LTV education and skills related queries, contact our Skills Implementation Leads: **gstt.panthamesltveducation@nhs.net**

Care Closer to Home: Strengthening Pathways

Aims

To strengthen regional pathways so that BCYP on LTV receive timely, safe and coordinated care, with care delivered closer to home wherever possible and driven by children's and families' best interests.

Expected benefits

- Shorter hospital stays and reduced avoidable admissions
- Clearer, more consistent decisions about the right place of care
- Earlier discharge planning, including proactive housing engagement
- Improved coordination between tertiary centres, DGHs, community teams and local authorities
- More BCYP on LTV cared for safely at home, improving quality of life for families

Key Successes 2025/26

01

Shaped National GIRFT Best Practice Guidance

02

Development of the Pan Thames pathway principles

03

Operational and Governance responses

04

Housing pathway: enabling discharge home

Looking Ahead

- Publish Pan Thames regional pathway principles to support consistent GIRFT implementation
- Continue to influence national LTV pathway development through GIRFT
- Strengthen neonatal-to-paediatric and step-down pathways to protect tertiary and PICU capacity by improving flow and transitions of care for BCYP likely to require LTV
- A clear Housing Recommendations Pathway, embedding the Duty to Refer as the default response to housing-related discharge delays and strengthening healthcare teams' confidence in its use
- Strengthen engagement with ICBs and Local Housing Authorities, including senior housing leaders

A Closer look at Key Successes 2025-26

01

Shaped National GIRFT Best Practice Guidance

The Pan Thames Paediatric LTV Programme team played a leading role in developing the GIRFT Best Practice Guideline for Children on Long-Term Non-Invasive Ventilation (2026). Pan Thames clinical leaders co-chaired the national working group and authored key sections, ensuring the guidance reflects real-world delivery across community, secondary and tertiary care.

The guidance sets out a clear end-to-end pathway supporting admission avoidance, timely discharge and shared decision-making, directly underpinning care closer to home. Pan Thames continues to support further national GIRFT work, including invasive ventilation guidance.

Impact:
More consistent decision-making, clearer admission avoidance and stronger discharge planning across England.

02

Pan Thames pathway principles

Working with STPN and NTPN, the Programme developed shared regional pathway principles covering LTV initiation, discharge planning, inter-hospital transfers and readmission pathways.

This principles document supports more consistent decisions about the right place of care to reduce unwarranted variation, minimise avoidable movement between settings and lay the foundations for consistent regional implementation of national guidance in 2026/27. The principles will be shared with the Networks clinical teams in 2026-27.

Impact:
Clearer decision-making on place of care across tertiary, DGH and community settings.

03

Operational and Governance responses

During 2025/26, a significant proportion of operational issues arose where responsibility for a child's LTV pathway spanned multiple Trusts, ICBs or sectors, particularly at points of transition, shared care and discharge. The Programme delivered a central coordination and governance function to support these complex cases, providing clarity on roles, responsibilities and escalation routes where local arrangements differed or were unclear. This enabled more consistent interpretation of guidance, supported aligned decision-making across organisations and reduced duplication and delay.

Impact:
Joined-up management of complex cases, with safer, more timely transitions and reduced pathway variation across Pan Thames.

04

Housing pathway: enabling discharge home

Emma Ashrafi, Housing and Welfare Lead

Housing remains a major non-clinical cause of delayed discharge for BCYP on LTV. In 2025/26, the Programme strengthened its housing pathway by promoting timely home suitability assessments, improving use of the Duty to Refer, supporting action on damp and mould, and strengthening relationships with Local Housing Authorities.

Specialist housing support from the programme's Social Welfare and Housing Lead directly enabled discharge in multiple complex cases by unblocking stalled processes, securing suitable accommodation more quickly and preventing unnecessary prolonged hospital stays. Educational videos for professionals and families are been developed to support earlier, proactive housing pathway planning.

Impact:
Stronger alignment across health, housing and local systems.

Case Study 1: From Hostel to Home

The challenge
A child established on non-invasive ventilation was medically ready for discharge, but the family were living in a homeless hostel, which was not suitable for care at home. Attempts by the tertiary team to contact the Local Authority had failed due to outdated contacts and lack of response.

Programme Impact
The Pan Thames Social Welfare and Housing Lead supported the Specialist Nurse by:

- Providing an up-to-date senior Local Authority contact
- Sharing a clear escalation route and template letter for unsuitable temporary accommodation
- Supporting appropriate use of housing and homelessness pathways

The outcome

- Within 13 days, the case was reviewed by the council's medical advisers
- A self-contained flat was offered shortly afterwards
- The family moved into the property the following day, enabling safe discharge

Why this matters
Targeted, system-level housing expertise prevented prolonged hospital stay and enabled care to be delivered safely at home.

"*Emma has been an invaluable resource… incredibly knowledgeable, supportive and proactive.*"
— Specialist Nurse

Case Study 3: When Temporary Accommodation Was Not Suitable

The challenge
An infant with complex medical needs could not be discharged to the family's previous home. Despite registering as homeless, the family received no suitable temporary offers, and social care involvement had ended.

What changed
Following contact from the child's local DGH, the Programme:

- Identified an alternative housing route within the Local Authority's allocations policy
- Escalated the case to the Director of Housing, drawing on established relationships
- Supported use of higher-priority housing pathways due to medical need

The outcome

- Within two weeks, the family received an offer of appropriate social housing
- Accommodation met the child's clinical and accessibility needs
- Discharge planning could proceed safely and without further delay

Why this matters
Where temporary accommodation cannot meet complex medical needs, early senior escalation can unlock appropriate long-term solutions and avoid extended hospital stays.

"Your support really helped make things move faster."
— Ward Manager

Case Study 2: Resolving Unsafe Temporary Accommodation During PICU Admission

The challenge
A family was placed in unsuitable temporary accommodation following a Duty to Refer. When the child was later admitted to PICU, concerns were escalated, but after a month no action had been taken — risking discharge delays.

What changed
The Pan Thames Social Welfare and Housing Lead:

- Escalated concerns directly to senior housing leads at the council
- Connected housing services and the Specialist Nurse
- Supported a joint meeting between the hospital and Local Authority

The outcome
A meeting was held within 10 days
Suitable temporary accommodation was secured within 9 days of the meeting
Discharge was achieved without further delay

Why this matters
Early escalation and system-level coordination prevented avoidable prolonged stay and supported smoother transition out of hospital.

"It is unbelievably reassuring to have you at the end of an email for support and advice."
— Specialist Nurse

Smarter use of high-cost technology and skilled resources

Aims

To improve value for money and sustainability in LTV services by coordinating the use of high-cost technology and specialist expertise at a regional level. The Programme aims to reduce duplication and unwarranted variation, release clinical capacity for direct care, improve system oversight, and ensure BCYP on LTV and their families receive safe, high-quality care delivered consistently across Pan Thames.

Expected benefits

- More efficient use of LTV Clinical Nurse Specialist (CNS) staff, through reduced duplication of training, procurement activity and non-clinical work
- Improved patient safety and experience, through more consistent equipment, training and service models
- Better system oversight, enabling informed commissioning, capacity planning and identification of avoidable cost
- Improved value for money, through coordinated approaches, reduced waste and economies of scale
- Greater system sustainability, supporting workforce capacity and equitable access to care across the region

Key Successes 2025/26

01

Regional digital training and housing and welfare resources

02

Strengthening regional LTV data and system oversight

03

Progress towards coordinated equipment procurement and maintenance

04

Parent and carer training videos

Looking Ahead

- Complete rollout of the regional paediatric LTV database across all London tertiary centres
- Use regional data to support strategic planning, commissioning and capacity modelling
- Progress implementation options for coordinated equipment procurement and maintenance
- Establish a regional equipment clinical forum to support standardisation, horizon scanning and shared learning
- Promote and evaluate uptake of digital training and family resources, with measurable impact on clinical time, length of stay and family experience

A Closer look at Key Successes 2025-26

01

Regional digital training and housing and welfare resources

In 2025/26 the Programme prioritised regional housing and welfare digital resources, alongside training, to support in reducing non-clinical pressure on LTV teams. Welfare content received 10,617 views across the year, with the Charity eBook accounting for 3,469 views (over 30%), demonstrating strong demand for practical financial guidance. Newly launched resources, including the Discharge Hub and Winter Welfare Hub, were well used during peak pressure periods. Housing page views declined while direct enquiries remained high, reflecting effective reuse of downloadable resources offline. Regional digital training and eLearning continue to complement this work by reducing duplication and releasing LTV CNS' clinical time. Refer to appendix B for the full list of housing and welfare resources.

Impact:

Reduced demand on LTV CNS's staff for non-clinical housing and welfare activity, improved productivity through shared training resources, and better use of scarce clinical expertise to support timely discharge and system sustainability.

02

Strengthening regional LTV data and system oversight

In the absence of national clinical coding or a centralised dataset for BCYP on LTV, the Pan Thames Programme continued to provide critical regional intelligence that can be utilised to support commissioning and service planning. During 2025/26, a regional LTV database was developed to track caseloads and discharge delays, with joint implementation planning undertaken with tertiary centres. Implementation was completed with one centre and commenced with a second, supported by strong regional collaboration to improve data consistency.

Impact:

Improved oversight of patient pathways and discharge delays, enabling more informed system-wide planning, identification of capacity pressures, and a stronger evidence base for future demand and resource modelling.

03

Progress towards coordinated equipment procurement and maintenance

Variation in paediatric LTV equipment procurement, servicing and maintenance continues to drive inefficiency and inequity, as highlighted by NCEPOD. During 2025/26, the Programme focused on establishing foundations for a more consistent regional approach. This included engagement with clinical, procurement and commissioning stakeholders, agreement to move towards standardised models, development of a regional service specification, and completion of a system-wide options appraisal.

Impact:

Alignment of stakeholders around a shared vision for safer, more efficient and better-value equipment provision, with clear foundations in place for implementation from 2026/27.

04

Parent and carer training videos

Feedback from families continues to highlight the emotional burden of transitioning from hospital to home which can have consequences on wider family life and the need for accessible resources to reinforce training.
In response, the Programme are co-producing a digital parent and carer training resource in collaboration with Evelina London Children's Hospital and families that will be free to access across the Pan Thames region.
During 2025/26, a multidisciplinary project team of experts oversaw development of these professional videos, and content was co-produced with families.

Impact:
The videos are expected to reduce in-hospital training time, improve parent and carer confidence, reduce reliance on specialist staff for routine support, and support timely discharge while maintaining safety and quality.

We sincerely thank the families and carers who shared their experiences and gave their time to shape this resource.

Their involvement, including sharing personal stories, allowing us to film in their homes and sharing family photos, has helped ensure this resource reflects real family life beyond hospital.

Their insights and feedback have been vital in shaping the scope of the resources ensuring that they meet the needs of others undergoing their training in order to care for a child on long-term ventilation at home.

Reducing unwarranted variation

Aims

During 2025/26, the Pan Thames Paediatric LTV Programme aimed to reduce unwarranted variation in access, decision-making and care pathways for BCYP requiring LTV. The focus was on embedding shared regional standards, strengthening system governance and improving coordination across organisations to ensure more equitable, safe and consistent care regardless of geography or provider.

Expected benefits

- Greater equity and consistency in paediatric LTV decision-making, care delivery and discharge planning
- Safer, more predictable pathways, supported by shared tools, standards and governance
- Improved flow and reduced delays, particularly at transition and discharge points
- Better use of specialist resources, reducing duplication and inefficiency

Key successes 2025/26

01

Benchmarking Across All Tertiary LTV tertiary centres

02

Strengthening Process for Ethical Decision-Making

03

Progress towards Continuing Care and Commissioning Consistency

04

Shared Learning and System Coordination

05

Mapping and Physiotherapy Capacity Building

06

Coordinated Operational Response and Governance

Looking Ahead

In 2026/27, the Programme aims to work with ICBs to embed shared standards into routine practice and commissioning, use audit and operational intelligence to target variation, and strengthen workforce and governance arrangements to support safer, more equitable paediatric LTV care across Pan Thames.

A Closer look at Key Successes 2025-26

01

Benchmarking Across All Tertiary LTV tertiary centres

The Programme completed a comprehensive Pan Thames paediatric LTV audit across all six London LTV tertiary centres (summer–autumn 2025), reviewing workforce capacity, caseloads, MDT working, discharge pathways and alignment with national standards - i.e. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD), and Midlands children's Long term ventilation network (MCLTVN).

Impact

- Established the first consistent regional evidence base to support benchmarking and quality improvement
- Identified shared risks (e.g. stretched workforce capacity, inconsistent community provision) and variation requiring system-level action
- Informed targeted Programme priorities and commissioner discussions

Findings demonstrated significant variation in consultant and CNS caseloads, universal under-capacity in dedicated LTV physiotherapy establishments, inconsistent use of shared clinical tools, and ongoing discharge delays driven by housing, workforce and funding complexity. A summary of the report is included in Appendix C.

02

Strengthening Process for Ethical Decision - Making

To reduce variation at the most contentious point of the pathway, the Programme supported development and regional adoption of a Pan Thames Ethical Decision-Making Framework and accompanying LTV consent documentation and a Family Booklet that was created with engagement from families of BCYP on LTV who have been through this experiences.

Impact

- Improved consistency and transparency in best-interest decision-making
- Strengthened MDT discussions and family involvement at an earlier stage
- Reduced reliance on informal, case-by-case approaches

During 2025/26:

- Three of six tertiary centres reported routine use of the framework (all or in part)
- One centre embedded the LTV consent process into standard practice
- The framework achieved formal endorsement from RCPCH, BPRS, the London Neonatal ODN, and both North and South Thames Paediatric Networks

These endorsements represent a significant milestone, positioning the framework as a credible, regionally agreed standard that supports safer, more equitable care.

03

Progress towards Continuing Care and Commissioning Consistency

In partnership with NHS England's London Regional All Age Continuing Care Team, the Programme co-developed London Quality and Safety Standards for the commissioning of LTV Continuing Care providers, adapted from best practice in the West Midlands.

Impact

- Increased consistency in commissioning expectations across ICBs
- Clearer education, governance and quality requirements for providers
- Improved oversight following serious incidents and commissioner feedback requesting structured guidance

Engagement and co-production with commissioners and providers was completed during the year, with formal consultation and ICB Boards approval planned for 2026/27.

04

Shared Learning and System Coordination

The Programme strengthened mechanisms to reduce variation in discharge practice through:

- A quarterly Discharge Support Forum, sharing learning on housing, welfare, continuing care and bereavement and providing professional peer support.
- Increased use of the Duty to Refer process for housing delays
- Targeted support from the Social Welfare & Housing Lead in complex cases

Impact

- Improved consistency in complex discharge planning across centres
- Reduced non-clinical burden on clinicians
- Earlier identification and escalation of system-level blockers to discharge

Feedback from over 100 professionals attending shared learning sessions consistently demonstrated high impact and intent to change practice.

05

Mapping and Physiotherapy Capacity Building

Melanie Amos, Physiotherapy Lead

The Physiotherapy Workstream completed a Pan Thames mapping exercise covering tertiary centres, L2 units, L1 hospitals and London community rapid response teams.

Impact

- Created the most complete regional physiotherapy contact network to date
- Improved signposting, support and system responsiveness for physiotherapy teams
- Informed education priorities and future workforce planning

Education delivery through webinars, study days and national AHP collaboration improved confidence and capability, particularly in settings with limited on-site physiotherapy support, supporting safer care closer to home.

06

Coordinated Operational Response and Governance

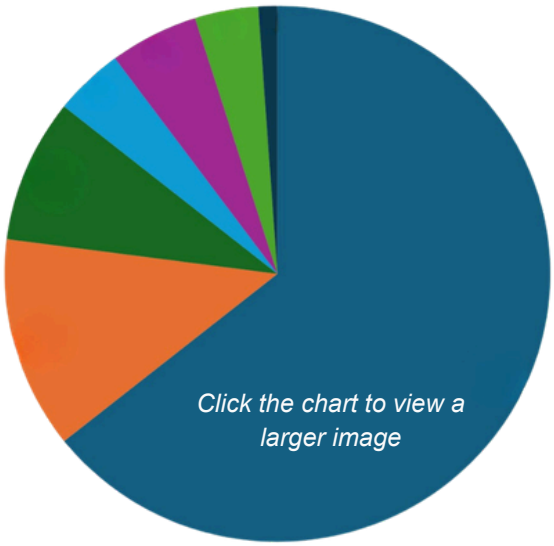
See Appendix D for a more detailed breakdown of Social Welfare and housing workstream enquiries.

In response to rising patient complexity and system pressure, the Programme embedded a region-wide operational response and governance workstream, providing a single point of contact for LTV-network related concerns crossing organisational boundaries.

During 2025/26, the Programme handled 266 operational enquiries, including enquiries through the Social Welfare and Housing workstream, identifying recurring themes.

Impact

- Improved visibility of emerging network-level concerns
- More coordinated responses to patient safety and pathway challenges
- Shared learning and mitigation of risks with potential network-wide impact



Colour Key	Enquiry area	n =	%
	Social welfare and housing	171	64.3%
	Guidance (clinical, physio, workforce)	34	12.8%
	Admin and documents (access, data, translation)	23	8.6%
	Pathways (including transition)	11	4.1%
	Training/education request (outside usual remits)	14	5.3%
	Equipment challenges	10	3.8%
	Care package/Continuing Care	3	1.1%

Operational analysis identified the following **recurrent system-wide themes** affecting BCYP on LTV.

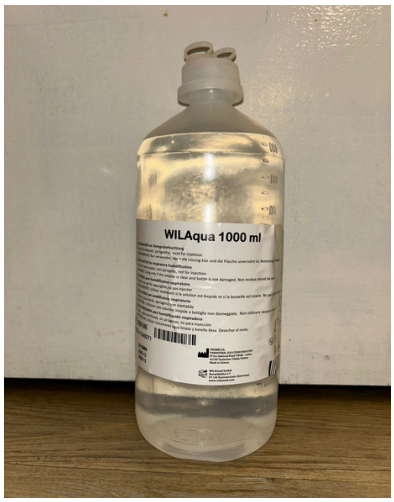
Non-clinical factors, particularly housing and continuity of care packages, were consistently identified as major drivers of delayed discharge and pathway instability.

Care spanning multiple Trusts, ICBs or sectors frequently led to unclear roles, variable escalation routes and inconsistent decision-making, particularly at transition and discharge points.

Recurrent issues related to the availability, prescribing and servicing of LTV equipment highlighted variability in local arrangements and wider system fragility.

Operational queries reflected unequal access to training and support, particularly outside tertiary settings, affecting confidence in delivering care closer to home.

The following case studies demonstrate how this approach reduced clinical risk, supported timely discharge and improved equity of access.



Case Study 1: Access to sterile water for ventilators in the community

The challenge
BCYP on LTV using MR850 humidifiers experienced inconsistent access to sterile water across boroughs, creating clinical risk, inequity and increased risk of hospital admissions.

What changed
A clinically approved alternative sterile water product was confirmed for use with MR850 humidifiers. This product is now available to order through NHS Supply Chain and will shortly be available for GP prescribing. It was then systematically communicated across the region to enable consistent access and implementation.

The outcome
Ongoing oversight of Drug Tariff progression and prescribing pathway implementation transferred to the NHSE Pharmacy team, working with London ICBs' Medicines Management teams.

Why this matters
Standardised solutions reduce unwarranted variation, improve safety and prevent avoidable system inefficiency.

Case Study 2: Welfare support to secure essential home equipment

The challenge
Following rehousing, delays in accessing statutory equipment risked prolonging hospital stay for a child on LTV.

What changed
Targeted welfare advice identified alternative charitable funding with rapid turnaround.

The outcome
Equipment was secured in time for discharge, avoiding prolonged inpatient stay and supporting the child's development.

Why this matters
Timely welfare intervention reduces discharge delays, avoids unnecessary costs and improves outcomes for children and families.

Thank you so much for reaching out to [the charity] and suggesting I contact them, what a success story, I know the family will really appreciate it and for the child not having to wait 6 months in the community for one will make a real difference to his development. "

Specialist Nurse

Case Study 3: Equipment access following the collapse of NRS

The challenge
The collapse of a national supplier disrupted access to profiling cot beds, delaying discharge and home leave for ventilated children.

What changed
The Programme coordinated a rapid multi-agency response, securing charitable funding options and sharing regional guidance with Trusts.

The outcome
Urgent equipment needs were met, enabling safe discharge and preventing extended hospital stays at a critical time.

Why this matters
Regional coordination mitigates system shocks, protects patient flow and ensures equity when local routes break down.

Appendix A

100% of L2 (within a DGH) have accessed Face to Face LTV education with the Pan Thames LTV Programme.

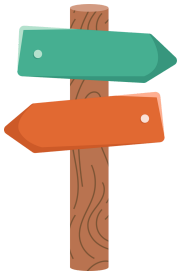
Note: Variations in the LTV population across STPN and NTPN reflect the geographical distribution of Hospital Trusts and differences in data collection.

DGH L2	ODN	Status Green - L2 open Amber - working towards	Local LTV Population (2023)	LTV Education
Royal Alexandra Children's Hospital	STPN	L2	23	• 2 Jointly delivered LTV Study Days 2024 & 2025
Queen Elizabeth Hospital	STPN	L2	32	• Train the trainer completed 2024 • LTV education delivered locally • Joint education in planning for 2026/7 with Pan Thames
St Peters (ASP)	STPN	L2 (Dec 2025)	12	• 4 Study Day (x3 2024/25 x1 2025/6 & • 2 shorter education episodes • Education in planning for 2026/7
William Harvey (East Kent Hospital)	STPN	Newly Commisioned	16	• 2 Study Days (2024/25 and 2025/26) • 1 Study Day booked April 2026 • STPN L2 day with LTV sim
Medway Foundation Trust	STPN	Newly Commisioned	32	• Train the trainer completed 2024 • LTV education delivered locally • Jointly delivered ½ day LTV Study Day 2025/26
Queens Romford (BHR)	NTPN	L2	49	• 2 Study Days (June 2025/26)
Chelsea & Westminster	NTPN	L2	2	• Jointly delivered LTV Study Day March 2026. • Further date booked September 2026
Northwick Park	NTPN	L2	3	• 2 Study Days (2024/5 and 2025/6) • 1 Study Day booked June 2026

Appendix B

Welfare: new webpages and web-based resources

You asked, we delivered



Discharge Hub

A depository of resources, all in one place, to support professionals with different steps of the journey from hospital to home, for a child on LTV.

Welfare Hub (poster and leaflet versions)
These resources can be displayed in patient-facing areas, or be given to families, with QR code links to some of our most popular welfare resources.

The above resources were requested to be developed by healthcare professionals within the network. Please continue to let us know if there is more that we can develop to support you to support your patients.

Housing

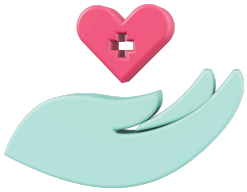
Housing Associations operating in the Pan Thames Region
This interactive map lists a range of Housing Associations that operate in our region, that families could explore contacting to see if they would consider direct applications.

Duty to Refer teams

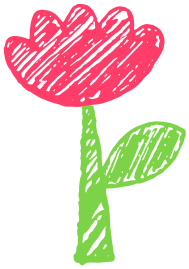
This interactive map lists all the Local Housing Authorities (councils) in the Pan Thames Region, with links to their Duty to Refer information pages.

Welfare Benefits, Grants and support in kind

Find a food bank tool and Support with food page
These resources can help families to identify places that can support them with accessing food if they are in need.



PIP Helper tool
We've integrated the Turn2us PIP Helper into our website. This is designed to support the entire way through the process of claiming Personal Independence Payment (PIP), which replaces Disability Living Allowance (DLA) for children above the age of 16.



SR1 Special Rules for End of Life
This webpage has information about the process of claiming welfare benefits for patients who are at the End of Life. Information includes who the Special Rules can apply to, which healthcare professionals can complete an SR1 form and some other frequently asked questions about SR1's and supporting patients who are at the End of Life.

Appendix C

2025 - 2026 Audit

Purpose of the LTV Pan Thames Audit

Across summer – autumn 2025, the Pan Thames Paediatric LTV Programme engaged with all six tertiary LTV tertiary centres to understand current practice, challenges, workforce capacity and alignment with national standards (NCEPOD and MCLTVN).

This audit exercise focussed on LTV teams, including physiotherapy staff. The team analysed caseload and workforce ratios and gathered examples of good practice to support regional quality improvement. The findings demonstrate consistent themes across workforce, MDT working, community pathways, and training.

The full audit reports can be accessed on our website ltv.services.com

Key Findings

1. Caseload & Workforce

- There is significant variation in LTV consultant and CNS caseloads, with some teams facing high pressure.
- All centres have less than 1 WTE dedicated to LTV physiotherapy, with most roles combined with wider respiratory responsibilities.
- Funding and staffing for physiotherapy remain inadequate across the region. Recruitment challenges persist, including a long-standing vacancy reported by one service. Although national and regional LTV standards require access to physiotherapists with appropriate paediatric LTV competencies and the ability to provide support across the week, none of the six centres currently has a dedicated physiotherapy establishment that meets these expectations in full. Persistent recruitment challenges further exacerbate service gaps, with one centre reporting a long-standing unfilled physiotherapy vacancy.

2. Use of Guidelines & Programme Tools

- Three of six centres use all or parts of the Pan Thames Ethical Framework; only one routinely uses the consent form.
- All centres use a Respiratory Action Plan (RAP)/ equivalent document. However, only two centres consistently embed physiotherapy components into RAPs, while others rely on internal plans or selective use. This variation limits standardised communication across the region. This variation limits standardised communication across the region.
- All centres use the Parent/Carer Competency Framework.

3. MDT Working

- LTV teams generally reported positive relationships with PICU/NICU teams but mentioned some challenges with ward capacity and skilled staffing.
- Outreach clinics and DGH links are variable; many teams rely on ad-hoc communication.
- Level 2 unit collaboration is variable across the region, reflecting different stages of maturity, with some notable examples of good practice.
- Most centres maintain effective relationships with DGH physiotherapists, but structured community pathways are lacking.
- Community physiotherapy capacity is reported as a “postcode lottery” in all centres. Limited outreach exists (2/6 centres), and formal peer support across tertiary and DGH physiotherapists is virtually absent.

4. Discharge & Community Challenges

- Housing is a major barrier to timely discharge across all centres.
- Other issues include social complexity, delays in care packages and unclear funding responsibilities.
- Use of the recommended “Duty to Refer” housing process is increasing, reflecting targeted support from the Pan Thames Programme.
- All centres provide comprehensive physio discharge documentation when needed, but only one third deliver consistent community handovers at point of discharge home. This represents a key gap in continuity of care, especially as community physiotherapy provision is universally reported as unreliable (0/6 centres reported adequate community provision).

5. Education & Competency

- All centres use Pan Thames education materials and e-learning.
- Family and carer training is robust across all six centres.
- Paediatric wards in the Tertiary centres sometimes lack confidence to manage LTV patients and this impacts PICU and HDU bed flow.
- Challenges persist in training paid carers due to turnover, availability and variable competency.
- Community physiotherapist training is minimal or absent in half of centres, and only two centres have fully governance approved competency frameworks.

6. Transition to Adult Services

- Variation exists across the region in transition age and processes.
- Centres linked to adult respiratory services have clearer pathways than standalone paediatric sites.

Key recommendations

- **Standardise Regional Use of LTV Tools**

Adopt the Ethical Framework, consent process and RAP, including embedding physiotherapy components, across all centres for consistent practice and safer transitions. This supports informed decision making, consistent family experience, smoother transfer and emergency care across tertiary and DGH settings.

- **Strengthen Workforce Capacity & Resilience**

Review workloads, admin support and clinical supervision to align staffing with caseload complexity. Physiotherapy peer support and workforce expansion was clearly identified as a need across the region with the current tertiary workforce being consistently stretched, with a clear additional gap in community physiotherapy provision.

- **Improve Structured Communication Channels with DGHs, Level 2 Units and Community Teams**

Implement regular MDTs, clear points of contact and routine shared-care planning to improve bed flow, support transfers closer to home, and increase DGH confidence in managing LTV patients. Stronger community integration, including physiotherapy community handovers, is required to support post-discharge continuity of safe and equitable care for children on LTV.

- **Support Other Wards to Improve Patient Flow**

Maximise access to Pan Thames LTV education support to increase ward competency training, utilise TCU-style models where possible and strengthen relationships with PICU/NICU teams to help with early interventions and improving flow.

- **Enhance Early & Robust Discharge Planning**

Consistently use the Duty to Refer early, utilise the WellChild Complex Discharge Toolkit and engage the Pan Thames Social Welfare & Housing Lead proactively in complex cases.

- **Standardise and Strengthen Transition Pathways**

Implement consistent regional transition timelines, ensure joint paediatric–adult reviews and clarify roles for equipment, consumables and engineering support.

Next Steps

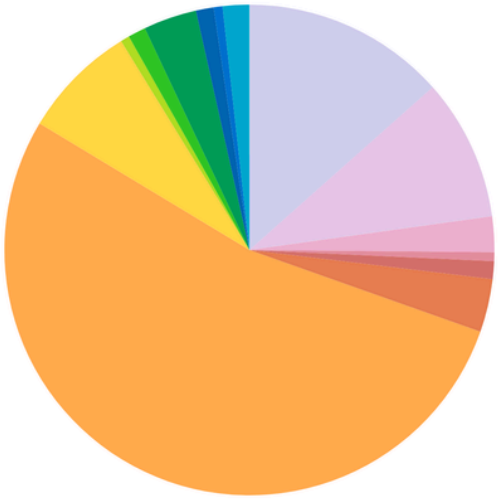
The Programme will use these findings to inform future priorities for our work. These recommendations will also be shared with clinical teams, commissioners, regional and national decision makers.

This exercise will be repeated every three years to support ongoing benchmarking, continuous improvement and network development across the region.

Appendix D

Welfare enquiries 2025/26

This financial year we handled 171 welfare enquiries through the Social Welfare and Housing workstreeam. A full breakdown of these can be found in the chart below.



Colour Key	Enquiry area	n =	%
	Benefits	23	13.45%
	Charity grants	16	9.36%
	Discrimination	4	2.34%
	Employment	1	0.58%
	Finances	2	1.17%
	Health	6	3.51%
	Housing	91	53.22%
	Immigration	13	7.60%
	Legal	1	0.58%
	Non-equipment grants (e.g., DHP)	2	1.17%
	Social	6	3.51%
	Support services (charity)	2	1.17%
	Travel	1	0.58%
	Utilities	3	1.75%

Click the chart to view a larger image

Top three themes

1) Housing

Over half of enquiries related to housing, highlighting it as the main non-clinical barrier to discharge. The Social Welfare and Housing Lead provided case-specific support to navigate local authority processes, identify decision-makers, and escalate issues: reducing delays, avoiding duplication of work for clinicians, and progessing stalled discharges.

2) Benefits

This was the second most common enquiry type, however over half of these enquiries appeared in Q1. The drop in Benefits enquiries after the Q1 Discharge Forum (which was focussed on benefits) suggests the forum helped address common queries. A small rise in enquiries again Q4 likely reflects increased public awareness following high profile benefits policy changes and media coverage.

3) Grants

Third most common enquiry area, but significantly reduced in comparison to previous years since the Charity eBook launch, which shows that self-help resources can meet needs and free clinician's capacity for complex cases. A temporary rise in enquiries from Q2–Q3 likely relates to supply issues after the NRS collapse.

Glossary

ACP	Advanced care plan
AHP	Allied health professional
APLS	Advanced paediatric life support
BIPAP	Bi-level positive airway pressure
CCHS	Congenital central hypoventilation syndrome
CCNT	Children's community nursing team
CCT	Continuing care team
CNS	Clinical nurse specialist
CPAP	Continuous positive airway pressure
CYP	Children and young people
EoL	End of life
EPALS	Emergency paediatric advanced life support
FFD	Fit for discharge
FFD-Hosp	Fit for discharge from hospital
FFD-ICU	Fit for discharge from ICU
HCP	Healthcare professional
HDU	High dependency unit
HRG	Healthcare resource group
ICD	International classification of disease
ICU	Intensive care unit
JCVI	Joint committee on vaccination and immunisation
LTV	Long-term ventilation
LTVRAP	LTV Respiratory action plan
MDT	Multi-disciplinary team
MV	Minute volume
NIV LTV	Non-invasive long-term ventilation
O2	Oxygen
OPCS	Office of Population Censuses and Surveys classification of interventions and procedures
PCC	Paediatric critical care
PCCS	Paediatric critical care society
PEEP	Positive end-expiratory pressure
PEG	Percutaneous gastrostomy
PEG-J	PEG jejunostomy
PEWS	Paediatric early warning score/system
PHDU	Paediatric HDU
PICU	Paediatric ICU
PIP	Peak inspiratory pressure
PPV	Pneumococcal polysaccharide vaccine
RSV	Respiratory syncytial virus
SOP	Standard operating procedure
SpO2	Pulse oximetry
Ti	Inspiratory time
Te	Expiratory time
Tr LTV	Tracheostomy long-term ventilation
Vt	Tidal volume

Pan Thames Paediatric LTV Programme

North Thames Paediatric Network
Connecting paediatric services

South Thames Paediatric Network
Transforming Healthcare for Children and Young People

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