



North Thames Paediatric Network

Connecting paediatric services

**Annual
Report
2024-25**



DOCUMENT HISTORY

Title	Annual Report for North Thames Paediatric Network 2024/25
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Owner	North Thames Paediatric Network Board

Date	15/08/2025
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NETWORK PRINCIPLES

The North Thames Paediatric Network is here to provide impartial clinical advice and expertise to all providers and commissioners within the three Integrated Care Systems it serves - North West London, North Central London and North East London (and also bordering East of England) to develop equitable, high standard services.

Overarching Principles:

- Putting patients and their families/carers at the heart of everything we do
- Removing variation in service provision across the Network to provide consistent quality of care
- Embracing innovation to improve the quality of care outcomes
- Collaborating on a system-wide basis

Strategic Ambitions:

- To support the delivery of high quality, safe, and effective services across the Network footprint that are delivered with the latest evidence based models of care and that meet the NHS Service Specifications and other key regional and national performance frameworks and standards deliver services in a
- Ensuring work plans are delivered within the financial resources allocated.
- To engage with regional, national and international stakeholders in our fields of expertise
- To help to develop a highly skilled, highly motivated, multidisciplinary workforce by embedding a culture of continuous education and workforce development throughout our network; facilitated by the development of partnerships with provider educators and HEE/universities
- To reduce health inequalities and ensure future services are developed that reflect local population health needs
- To promote the GIRFT principle of 'care closer to home', ensuring patient pathways align with local systems and are more streamlined for patients/families/carers.



CLINICAL DIRECTOR'S OPENING WORDS



I was appointed as one of the two new Clinical Directors of the Network in Summer 2024. I was fortunate to have worked with the Network as the clinical lead for Paediatric Emergency Medicine (PEM) for a few years before I was appointed. I thought I had some idea of the breadth & scope of the work of the Network from my perspective as PEM lead, but I rapidly learned that the already impressive range of activities I knew of, was only a small selection of the full work the Network was engaged in. I have been impressed with the huge range of organisations the Network engages and interacts with, from individual DGHs all the way through to National organisations. I have also constantly been reminded of how highly regarded the Network is by so many of these different organisations.



The Network is a relatively small team of core individuals, supported by an equally small group of dedicated clinicians who collectively make a much bigger impact on children's services across North London than anyone might expect.



At a time when there is more uncertainty about health systems than has been present for the last decade, it is even more important than ever to maintain a strong central voice for children and to continue to be a beacon for education, best practice and collaborative working. I have no doubt that the Network will continue to be this voice.



Dr Giles Armstrong
Network Co- Clinical Director
Paediatric Emergency
Medicine Consultant
Royal London Hospital

AREAS OF FOCUS

System Partnership

The Network plays a key role in encouraging multi-system collaboration and partnerships in order to ensure the safest, most cost efficient and streamlined pathways of care for Children and Young People. The Network aims to continue to build and integrate its' workplan into that of Integrated Care Boards and regional plans.

Education

The Network prides itself on offering free expert educational programmes across the Network area. This is multi disciplinary and aims to standardise the level of care offered across the Network's tertiary and secondary paediatric units. The Network has a free online educational portal 'Moodle' platform where staff can register to access more content and guidance.

Expert Advice

The Network employs a multi-disciplinary team of experts to provide advice and guidance to key system partners. In the past year the Network has played a key role advising on all paediatric pathways and as an expert negotiator for mutual aid solutions in the areas of cardiac, critical care, surgery and gastroenterology.

Digital Innovation

The Network has invested in the future digital innovation of paediatric healthcare services by funding innovative pilots and trials. The recently appointed Digital Innovation Lead brings an expert nursing background and has helped lead innovations such as Virtual Ward trials, development of the Universal Care Plan and multi system referral solutions for paediatric heart transplant.

Data Solutions

Key to all network improvement work is accurate and transparent data. the Network continues to improve its Paediatric Digital Sit Rep system which provides the system live paediatric critical care and ward bed information.

Moving forward the Network will be looking to further develop it's data and research capabilities.

Surge Support

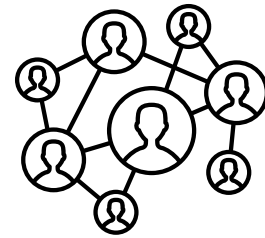
Since Covid 19 the Network has developed a crucial escalation system across the Network area to ensure there are robust pathways of escalation in time of surge and Winter pressures.

Moving forward the Network has been at the centre of developing a national set of Paediatric Intensive Care Contingency Levels.

FUNDED WORKSTREAMS

Nationally funded Operational Delivery Networks

- > Paediatric Critical Care Network
- > Congenital Heart Disease Network
- > Paediatric Cancer Network
- > Teenage and Young Adult Cancer Network



Funding is received in region from national allocated funds.
The Networks have national service specifications.

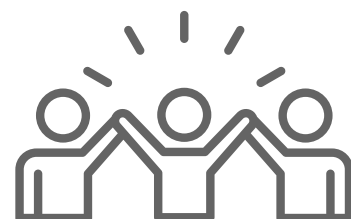
Regional funded projects

- > Quality Improvement/Workforce initiatives
- > Pan Thames Long Term Ventilation Programme
- > Paediatric Critical Care competency roll out



Other workstreams and priorities

- > Long term plan funded Epilepsy nurse specialist pilot and mental health pilot
- > Gastroenterology, Neurology, Transition, Emergency Pathways



NETWORK SPECIALISMS



**Cancer:
Paediatric**



**Cancer:
Teenage & Young
Adult Cancer**



**Paediatric
Critical Care**



**Emergency
Pathways**



Epilepsy



Gastroenterology



**Long Term
Ventilation**



Neurology



**One Heart
Congenital Heart
Disease Network**



**Surgery
in Children**



**Data Analytics
& Health
Inequalities**



**Education &
Shared Learning**



**Risk & Governance/
Quality & Safety**



**Paediatric
Winter/Surge
Planning**

NETWORK MANAGEMENT TEAM



Kate Plunkett-Reed
Network Director

Strategic Leadership
Network Manager
Congenital Heart Disease
Martha's Rule Implementation
Lead
Pan Thames LTV Programme
Paediatric Critical Care
Winter Planning Lead



Lauren Martin
Deputy Network Director

Operational Leadership
Network Manager Paediatric
Cancer and TYA Cancer
Workstream manager for
Neurology, Epilepsy
Universal Care Plan Lead
Anaesthetic Workstream Lead



Tanya O'Driscoll
Nurse Director

Nursing Leadership
Surgery in Children
Network Lead
Healthcare Play
Emergency Pathways

Network Clinical Directors



Dr Giles Armstrong



Mr Nic Alexander

The Network Clinical Directors work together to provide clinical leadership support across the Network workstreams areas and to provide guidance to the individual work programme clinical leads

NETWORK SUPPORT TEAM



**North Thames
Paediatric Network**
Connecting paediatric services

Operational, Projects and Data Team



Shah Hussain
Senior Data Manager &
Business Analyst



Agnieszka Sprawka-Koszel
Junior Data Analyst



Jessica Kinghorn
Junior Project Manager

NETWORK NURSING, EDUCATION AND QUALITY TEAM



Amy Hunter
Lead Educator
Risk & Governance Lead
PICU Lead Nurse
Network Martha's Rule
Implementation Lead



Patrick Duff
Network Educator
Paediatric Critical
Care Expert



Kimberly Porter
Network Educator
Surgery in Children
Expert

REFLECTIONS FROM THE NETWORK DIRECTOR



Kate Plunkett-Reed
Network Director
North Thames Paediatric Network

2024/25 has been an exciting and interesting year in Paediatrics, both regionally and nationally. In October the government announced a new 10 Year Health Plan for the NHS. One of the drivers was the worsening child health outcomes and increasing pressures on paediatric services. Together with this, the continued development of Integrated Care Systems and the move to delegate specialised commissioning to their Boards has led to a greater need for the Network to collaborate with all system partners, share learning and advise on commissioning priorities. To reflect this, the Network team has grown even further - recruiting additional educators, enhancing its' data and business intelligence support and bringing in expert leadership in digital innovation.

Whilst the core priorities for the Network centre around the nationally funded operational delivery networks of Paediatric Critical Care, Surgery in Children, Congenital Heart Disease and Paediatric and Teenage Young Adult Cancer, the Network pushes its boundaries and furthers its expert support in Neurology and Epilepsy, Gastroenterology, Emergency Pathways and Risk & Governance. We are also delighted to have been awarded additional funding recognising our excellent bid for a Network pilot for Martha's Rule.

The challenges faced are the same, workforce and resource, need to be as cost efficient as possible and an ever changing system to navigate. I was proud in March to have been invited to represent at the World Health Organisation and United Nations summit in Copenhagen. Part of an expert group of select stakeholders, we came together as a global team to plan for a healthcare systems faced with these challenges.



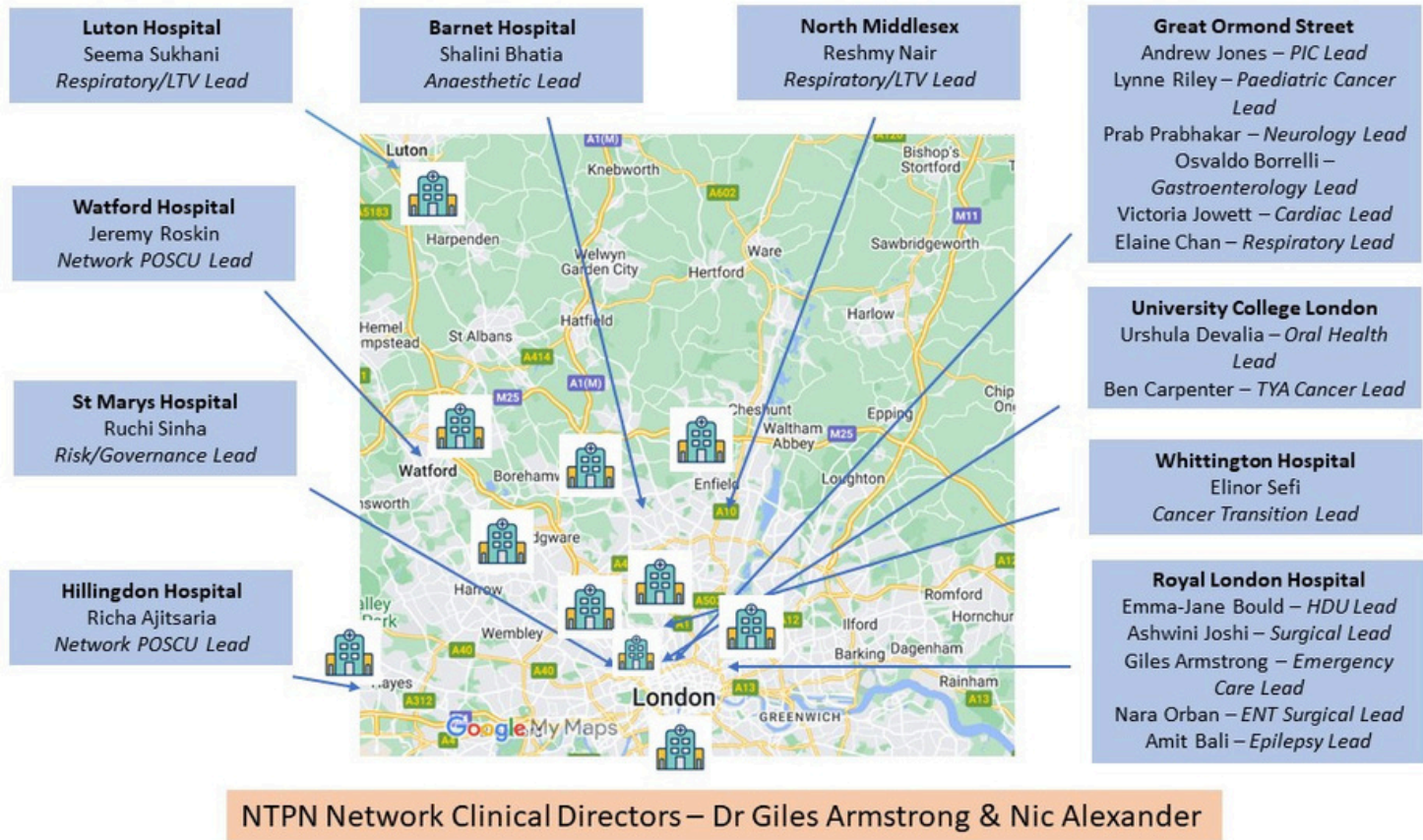
Meeting with
World Health
Organisation

I will leave my Network Director post in 2025 after 6 years. I want to take the time to thank all of the stakeholders for their incredible support and in particular the Network team - they really are the most passionate, expert group who I know will continue to work hard for our Children & Young People



CLINICAL EXPERTISE

NTPN – A Network of True Clinical Collaboration



The North Thames Paediatric Network prides itself on being fully representative of its Network member hospitals. There is clinical representation from most trusts and the three Integrated Care Systems of North West, North Central and North East London.

Having clinical expertise and leadership from both tertiary and secondary care allows for shared experiences, learning and challenges from both sides of the acute pathway. It ensures the work of the Network is truly led by its' stakeholders.



NETWORK HOSPITALS



The Network works with acute paediatric service providers across North West, North Central and North East London as well as bordering hospitals in East of England that have pathway flows into North Thames.



Throughout 2024-25 the Network has continued to strengthen its relationship with quarterly Board meetings, monthly MS Teams calls with network hospitals, site visits and delivery of education onsite at local hospitals. The Network hosted a face to face stakeholder review meeting in May 2024. The Network has also continued to work with regional partners in NHS London and East of England as well as National partners e.g. GIRFT and national operational delivery network teams and CRGs.



The Network continues to be hosted by Great Ormond Street Hospital for Children and has an office working space located onsite.

CHILDREN AND YOUNG PEOPLE POPULATION MAP

mid-2023 estimates
CYP (<18 years)



21%

of London's total
population are
children/young people

22.71

London's average
deprivation score

North West London

Total CYP (<18) Population: 441,566 (21%)

Total Adult (18+) Population: 1,701,611

Deprivation (IMD) Average Score: 21.17

North Central London

Total CYP (<18) Population: 298,799 (21%)

Total Adult (18+) Population: 1,141,481

Deprivation (IMD) Average Score: 23.33

North East London

Total CYP (<18) Population: 465,869(23%)

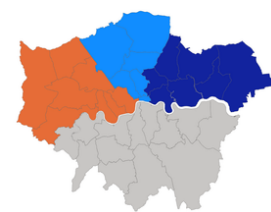
Total Adult (18+) Population: 1,568,416

Deprivation (IMD) Average Score: 26.33

Most Deprived ICB in London



DATA ANALYTICS & HEALTH INEQUALITIES

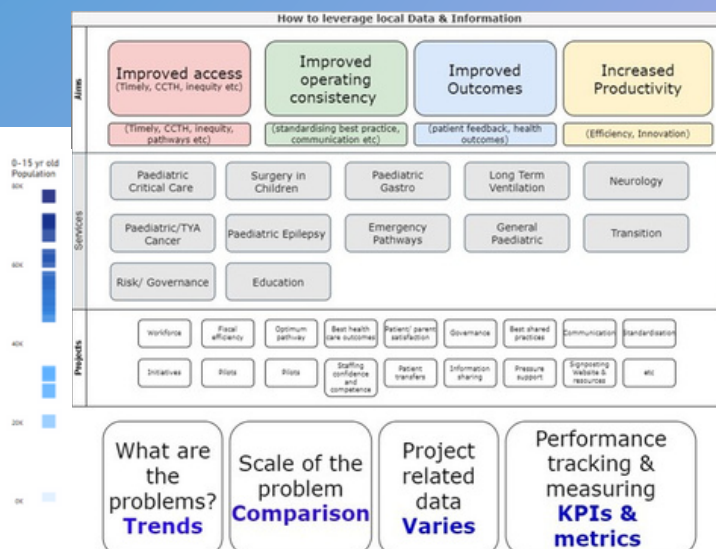
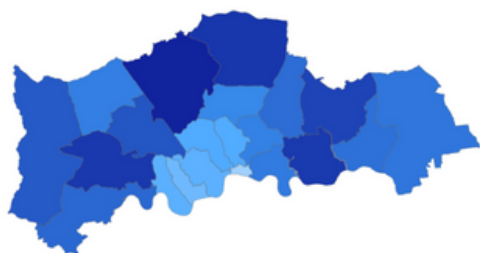


The Network continues to deliver a multitude of projects in various paediatrics services and workstreams equipped with the necessary data required to make calculated and well-informed strategies, projects, and suggestions for streamlining the delivery of paediatric health care. Keeping in mind the Network aims and objectives, the team co-ordinate with the Networks Data team to extract, validate, calculate, and utilise a variety of data resources to plan and execute projects.

Did you know?

The North Thames Paediatric Network covers an approximate area of 20km by 58km in London, north of the river Thames and within the bounds of the M25. Some NTPN health care pathways, speciality services & other health care activity also frequently include patients that live on the borders of London from neighbouring ODN's. Within this region:

- Mid 2022 estimates of the NTPN population were 5.5 million people. Of which 1.2 million (22%) were under the age of 18.
- The network resides across 3 ICB's and 21 Local Authorities. In a national survey conducted in 2019, the office of national statistics reviewed multiple variables to calculate an IMD (Indices of multiple deprivation) score for each Local Authority. The findings of which show that 2 NTPN boroughs are within "the 20 most deprived boroughs" of 317 of national Local Authorities.
- London health demands differ to that which is found in other major cities. Some variables that would contribute to this difference includes London diverse population, population density and access to health services.
- 209 GP surgery's
- 14 Secondary units + 5 Border units
- 4 Tertiary Units



Data at the network?

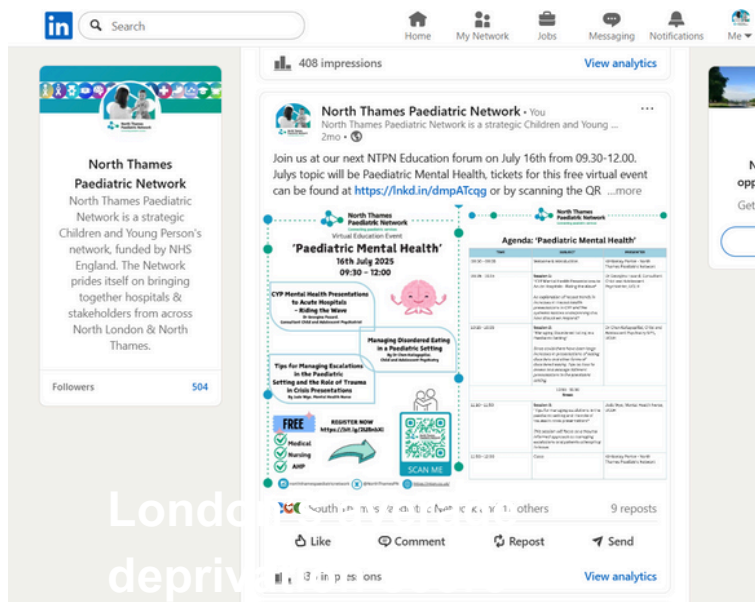
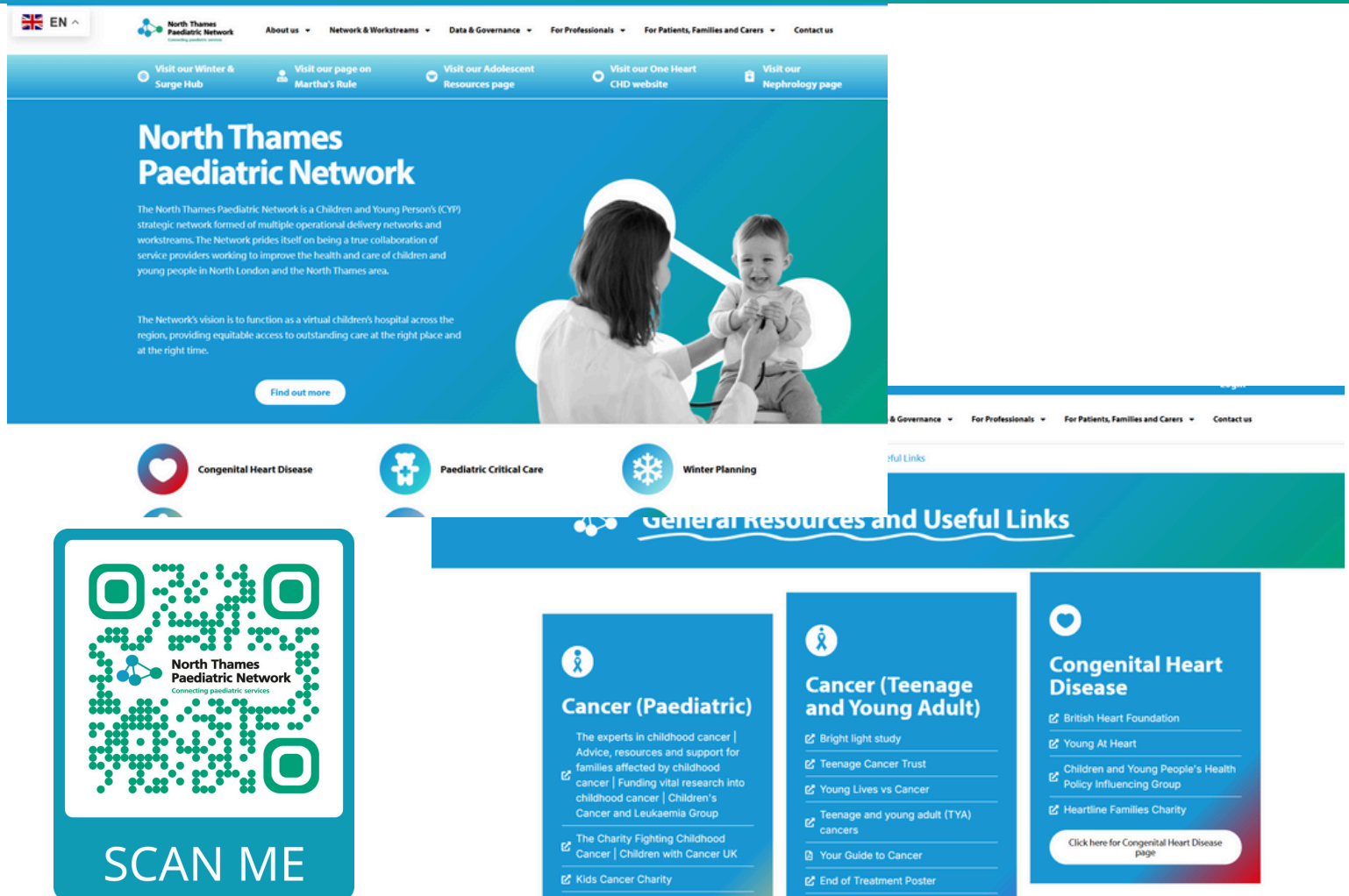
The Network continues to work with our stakeholders and commissioning partners to acquire access to additional data resources. This is to ensure the data that is utilised is up to date and paint a clear picture of the network's strengths (for sharing best practices) and areas of improvement. Whilst aiming to increase informatics resources, the Network also ensures a governance driven approach is taken to handle all new resources. With access to more comprehensive datasets, the Data team aims to incorporate technological advancements into projects including Data science modelling & AI.

Applications & useful resources

The Network continues to utilise a variety of applications to collect data from stakeholders. Some of the data contributes to service specification mandated data submissions, monitoring trends, scaling network level issues, recording KPI's and more. Stakeholder capacity is recorded on the MediTrack system and the logging of network level risks (please read the risk and governance section of the report for a better understanding on how to utilise this resource) are recorded on NetTrack. The network dashboard is a locally used resource that creates a single point of access to all relevant data tailored to each speciality. It is an ever-changing platform to suit stakeholder needs. Link to these systems can be found via the network website; <https://ntpn.co.uk/network-data-systems>.

WEBSITE AND SOCIAL MEDIA RELAUNCH

The Network has a wealth of resources, educational videos, guidelines and expertise. This can be accessed via the Network website. Free live education events and webinars are advertised via our LinkedIn page.



WEBSITE VISITORS - 2,800
WEBSITE VIEWS - 7,200
OVER 100 PROFESSIONALS
REGISTERED
OVER 250 VIEWS OF
EDUCATIONAL VIDEOS

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Thames Paediatric Network

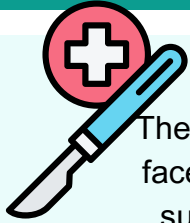


*How Network funds
are having a direct
impact on patient care*

2024 /25

Key Impact Areas

Education Support



The Network has recognised the challenges faces by local secondary paediatric units in supporting children with some paediatric surgery presentations, especially since Covid 19 and subsequent recovery challenges. In response, the Network education programme has expanded in 2024/25 to include more surgical and anaesthetic education training including a dedicated **recovery skills** course, delivered at **Great Ormond Street Hospital for Children**, a pre-assessment course and innovative education such as virtual reality sim based training.



Martha's Rule

The Network received national recognition in paediatric critical care and was awarded funding from the **National Patient Safety and Quality team** to undertake a network wide pilot for **Martha's Rule**.

This is planned to include:

- Dedicated **mediation** training for staff
- Catered **peer support**, recognising gaps in skills supporting deteriorating children
- A **health inequalities** focus on access to services including appropriate language translation

Risk & Governance

The Network has successfully rolled out a network level pathway issues and risk digital tool '**Net Track**'.

This has become a widely used tool for paediatricians to log multi system pathway issues and challenges. This has led to a number of **collaborative expert led M&M discussions**, guideline creations and improvements to pathways and services for **children, young people, their families and carers**.



The Network continues to put **quality and safety at the heart** of what it does and is working with specialty partners to develop network wide risk and governance frameworks

Winter & Surge Planning

The Network has continued to evolve its' support to hospitals and Integrated Care Systems in further developing **winter and surge planning** for **paediatrics**.

A networked escalation system has proved incredibly successful with a reduction in escalations to the Network and only **one out of region transfer** throughout the whole of Winter 24/25.

The Network has readied itself to develop and circulate **urgent guidance** e.g. measles and continues to work closely with the Children's Acute Retrieval Service (CATS)



CHILDREN AND YOUNG PEOPLE

KEY STATISTICS

Why the Network's continued work and advocacy for Children and Young People is important

Accident & Emergency (A&E) attendances for 0–4 year olds increased from 762.6 to 797.3 per 100,000 children (from 2021–22 to 2022–23)



According to an NHS survey, about 1 in 8 children aged 2 to 10 in England are obese



26.9% of 5-year-old children had obvious enamel and/or dental decay (i.e. at least one decayed tooth)



A 2024 article reports that in May 2024, there were 362,900 people waiting for paediatric care in England (i.e. children's elective waiting backlog)

Part of the figure above, “well over 8,000 children waiting more than a year”.

RCPCH notes that “waiting list for community child health services is almost 270,000” (which includes e.g. speech & language therapy, autism assessments) as of early 2025

In 2023/24, 78,577 young people were waiting over a year for NHS mental health treatment; of those, 44% were waiting over two years.



DIGITAL PROJECTS AND INNOVATION

Virtual Wards

Our CHD Lead Nurse Adrienne has been co-designing the first Great Ormond Street Virtual Ward together with the DRIVE team and the CNS team. A 6 month proof of concept in progress for 'cardiac fragile infants' with brief written, procurement processes completed, baseline data determined and customisation / platform development to start in Autumn 2024.

Success will pave the way for across the board service virtual ward uptake including – transplant, anticoagulation, inherited cardiac and single ventricle and shared learning for other NTPN speciality areas.



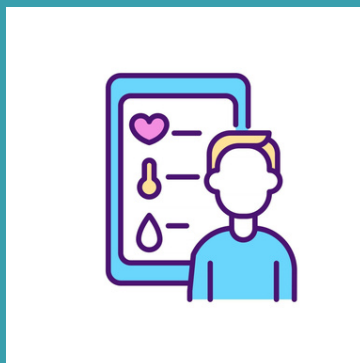
Universal Care Plan

The Universal Care Plan is a London-wide digital health passport that is integrated with electronic patient records and the NHS app, as well as accessible via the web, to facilitate better, more joined-up care for patients across multiple providers, including London Ambulance Service and Emergency Departments. In January 2025, the Babies, Children and Young people fields on the Universal Care Plan (UCP), developed by the North Thames Paediatric Network team, went live. These fields are generated using conditional logic so that they appear if the age of a patient is under 18 years old. This is a big success for the team as it means that children will have UCPs with age-appropriate questions and sections for clinicians to complete. The North Thames Paediatric Network continues to work closely with the Universal Care Plan team to expand the reach and engagement (such as plans to adopt the UCP in CYP cancer), generate improvements (such as an easier process for proxy access for parents) and develop bespoke designs for specific conditions, such as epilepsy (which has now reached its prototype stage and is set to launch later in 2025). In future, we plan to focus on additional conditions such as long term ventilation and also to develop transition fields for children aged 13–18, to facilitate developmentally appropriate healthcare and a smooth transition between children's and adults' services.

Digital Patient Tracker

For some patients with complex health conditions and multi system or hospital access needs (e.g. LTV, Cardiac/CHD, Oncology) there is a need to create network patients trackers to understand patient pathways. Work has been taking place to understand these could be developed.

These patient trackers would be particularly useful for when CYP patients transition to adult services.

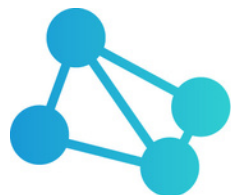


Innovation in Healthcare

Two of the Network team, Kate and Adrienne have been part of an Innovation in Healthcare programme in partnership with Imperial College London.

The course has been a collaboration between public sector and private sector healthcare colleagues.

**Imperial College
London**



North Thames Paediatric Critical Care ODN



Dr Emma-Jane Bould
Level 2/HDU Lead
Consultant Paediatric
Intensivist
Royal London Hospital



Dr Andrew Jones
PICU Lead
Consultant Paediatric Intensivist
Great Ormond Street Hospital for
Children/Children's Acute
Transport Team (CATS)

Key Achievements 2024/25

Investment in increased Level 2/ HDU Level Care

Funding secured for continued investment for additional HDU Beds at Northwick Park, Queens and Royal London.

Investment for third team at CATS during November-March.

Ongoing engagement and support for Level 2 newly commissioned sites.

Shared learning level 2 event ran in October 2024 in collaboration with South Thames Paediatric Network.

Winter and Surge Planning/ Support

Early Surge Planning: including lead nurses meeting with all specialist centre bed managers. Improving communications.

NTPN escalation group being utilised by stakeholders and fewer direct escalations to NTPN Paediatric Critical Care team.

One out of region transfer due to capacity and speciality reasons, a reduction on previous years due to collaborative working.

Surge pack development and education provided for our stakeholders pre and throughout Winter.

Workforce

Ongoing work with matrons for Paediatric Critical Care to create a sustainable workforce.

In September 2024 the Network ran a Pan-London Paediatric Critical Care workforce workshop in collaboration with NHS England. Aims of the session were to come together to share workforce success and challenges and identify projects for workforce development.

Level 2 workforce development supported by our education programme, enabling upskilling and care closer to home.

The Network has received funding from the NHS England regional team to launch a Quality Improvement project centred around creating efficiencies in the Paediatric workforce.

NHSE Martha's Rule Network Pilot

Successful Network bid in collaboration with CATS for Martha's Rule in May 2024. 1 of 3 Operational Delivery Networks selected. Stakeholder led bid.

Implementation plan developed and recruitment of the team which includes: 3 x family support nurses, 4 clinical leads and 1 x clinical fellow. The team started in April 25.

16 paediatric unit trust's from North Thames joining the pilot.

Continued work with NHSE and national quality and safety partners to support our trusts with local plans and implementing the network pilot catered to Paediatrics specifically.

Future Plans 2025/26

- Launch of the Network Martha's Rule pilot.
- Partnership with Patient Safety Collaboratives and Integrated Care Board partners re learning and expansion of the Network Martha's Rule pilot.
- National Paediatric Early Warning Score support for NTPN pilot trusts
- Roll out of Paediatric Critical Care workforce support and Quality Improvement initiatives.
- Secondary review of level 2 capacity with NTPN with a focus on North Central London
- Review of total number of beds and surge beds pre winter 25/26
- Review and update all Paediatric Critical Care Guidelines
- Review our daily data field collection, inline with national advice for PCC requirement
- Support of roll out of Paediatric Critical Care Digital Nursing Competencies across Network hospitals.



FOCUS ON LEVEL 2/HIGH DEPENDENCY INVESTMENT

Paediatric critical care (PCC) in London region received transformation funding through the Service Development Fund (recurrent £3.5 million across London) through 24/25 to add additional High Dependency (HDU) level care capacity to the Network. This transformation activity is monitored and progress to deliver supported by the North Thames Paediatric Network.

The Network undertook an intensive review of existing capacity, together with data that determines demand (e.g. emergency department admission data, surgical admission data, data on number of children admitted on long term ventilation) in order to establish a number of centres that would qualify for priority investment. Those hospital sites were determined to be: Northwick Park Hospital, Queens Hospital Romford and to add to the existing beds at the Royal London Hospital. In North Thames, the decision was also taking to support a permanent third team through Winter for the Children's Acute Retrieval Service (CATS) as this is a fundamental element of Paediatric Critical Care support and allows additional HDU retrievals.

Stakeholders described investment having a range of positive outcomes for patients and families, staff, the unit and wider PCC. For staff, the funding was reported to have improved staff confidence, satisfaction, wellbeing and retention. For the units, the impact varied depending on the type of hospital. The reported impact includes: reducing L2 and L3 occupancy; faster step-downs; reduced refusals; and more consistently maintaining staffing ratios. The CATS team had a lower refusal rate, which was described to have facilitated more timely transfers and faster step-downs. The team was also able to complete more paediatric care transfers.



London - North Thames: next steps

- Work closely with commissioners and ICB to help target resources where needed
- Aim for equality and equity in HDU provision and pathways closer to home
- Continue to help develop the level 2 services
- Provide education, support and shared learning
- Keep children and families at the centre

NCL
0-16 Population = 378,000
IMD score = 5.1
Paeds PIC/CIC/NIC Beds = 47
Paeds Level 2 Beds = 8 non GOSH
Paeds DGH Beds = 86 (inc GOSH)

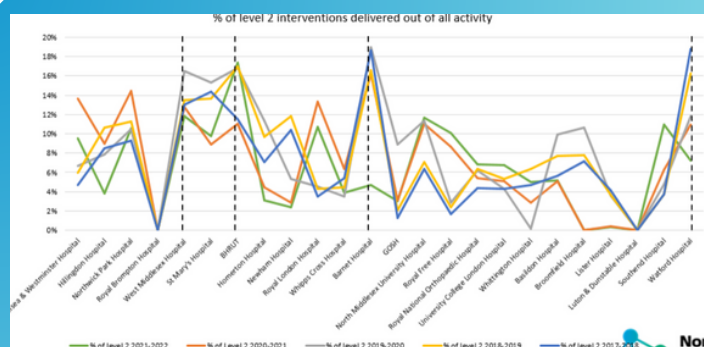
NWL
0-16 Population = 398,000
IMD score = 5.0
Paeds PIC Beds = 27 (inc RBH)
Paeds Level 2 Beds = 18
Paeds DGH Beds = 141 (inc RBH)



NTPN (Excluding EoE units)
0-16 Population = 1,244,000
IMD score = 4.7
Paeds PIC Beds = 82
Paeds Level 2 Beds = 41
Paeds DGH Beds = 389

NEL
0-16 Population = 468,000
IMD score = 4.2
Paeds PIC Beds = 8
Paeds Level 2 Beds = 11
Paeds DGH Beds = 162

* Population data are estimates from ONS 2020
* Index of Multiple Deprivation (IMD) data is based on estimates from ONS 2019 (1 to 10 where 1 is most deprived)
* Includes 22/23 SDP HDU Beds



For children and families, stakeholders described: increased capacity and staffing improved the quality of care and safety for patients; patients were able to stay closer to home; and improved wellbeing and satisfaction of families.





WINTER & SURGE PLANNING

For Winter 24-25 the future plan of the Network is to expand upon the existing Paediatric Operational Escalation Levels (POPEL) and align them to local hospital provider and ICS escalation and POPEL plans and also to integrate POPEL levels within the Network MediTrack Sit Rep System that informs bed capacity and surge.

OPEL score	Description	Footprint
POPEL 1	Normal - Capacity within individual providers and therefore across the region is meeting demand	Local level
POPEL 2	Low surge - Restricted capacity within one or more providers with mitigations in place mostly meeting demand across the region	Local and regional ICS level NTPN
POPEL 3	Capacity significantly restricted within multiple providers leading to delays in treatment likely across the region	Local and regional ICS level NTPN
POPEL 4	Regional and supra regional capacity severely restricted with delays to treatment highly likely across the region and wider	Local, regional, NTPN and supra regional level leading to National Incident Coordination if required

	Risks	Recommendations
Infection Control and Immunisations	• Rapid point of care testing for RSV, Influenza and COVID testing results needed to enable safe cohorting of patients. • Limited access to cubicles for isolation of patient • Unwarranted variation in applying NTPN IPC guidelines for acceptance of repatriations. • RCPCH guidance does not provide advice on the management of pyrexia. • Staff sickness and unvaccinated staff (Winter Flu/Covid).	Local Trusts/Organisation/ICS Level • Facilitate flu, covid and MMR vaccination ASAP for all staff • Facilitate the early start for the Palivizumab vaccination for vulnerable infants / children – Oct 2023 NTPN • Re-circulation of NTPN/STPN IPC guidelines • Re-circulation of RCPCH and PHE guidance 2023 NHSE/NTPN/STPN IPC Guidance – letter format 2023 NHSE/NTPN/STPN IPC Guidance – poster format RCPCH: National guidance for the management of children in hospital with viral respiratory tract infections (2023) RCPCH (last modified 24 October 2023)

The Network has also worked closely with infection control partners and the London Region Infection Control Team to develop guidance on the transfer and step down/cohorting of patients in addition to advice on testing and immunisation.



WINTER & SURGE PLANNING



London Critical Care Winter Planning for 24/25: Overview and next steps for Paediatric Critical Care Networks

- The surge plan will outline current provision, surge potential, rate limiting factors & potential risks, local surge strategy planning to consider / include (NTPN Recommendations), explore recommendations for potential ICS level support, explore recommendations for potential NHSE level support and outline NTPN Level support.
- PICU is a regional resource and as such is split from General Paediatrics which should, where possible, be managed locally within ICS sector footprints. There is a focus this year on Level 2 care and ensuring additional commissioned capacity is in place to support with step down and flow.
- It will focus on areas that should be considered as priority areas for building and ensuring the most robust resilience strategies are in place across the system. These would, if implemented, preserve standard clinical pathways, and support seamless and safe service delivery across the region during peak periods.
- Identify the need for additional resources and funding to support this surge plan and the routes to funding requests via NHSE/ICS partners to enable this.
- The surge plans will describe the arrangements for supra regional planning and mutual aid.

Priorities

- Capacity – PICU/Ward Beds/Level 2
- Equipment and Consumables
- Workforce/Staffing/Training
- Transport
- Infection Control
- CAMHS
- Continuation of Elective Surgery
- Adult Surge Plans
- Environment
- Governance
- Mutual Aid

Partnership Working

- Acute Trusts/DGHs
- Tertiary/PICU Centres
- ICS Partners
- NHSE
- CAMHS
- Transport (CATS/LAS)
- London Adult Critical Care Network
- Neonatal Network
- Cardiac Networks
- London Region Communications Team (incl. 111)
- RCPCH

Risks/Caveats

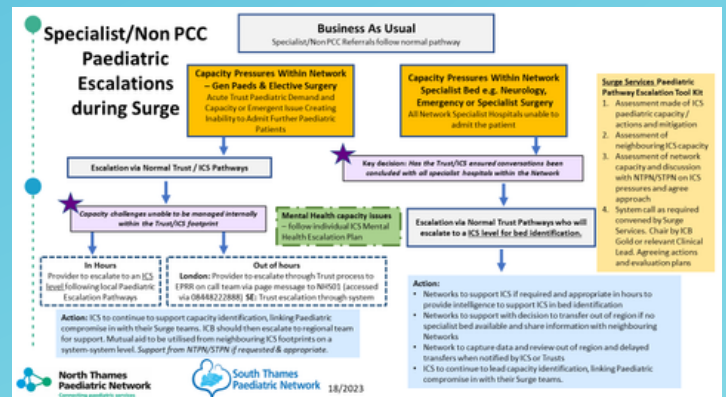
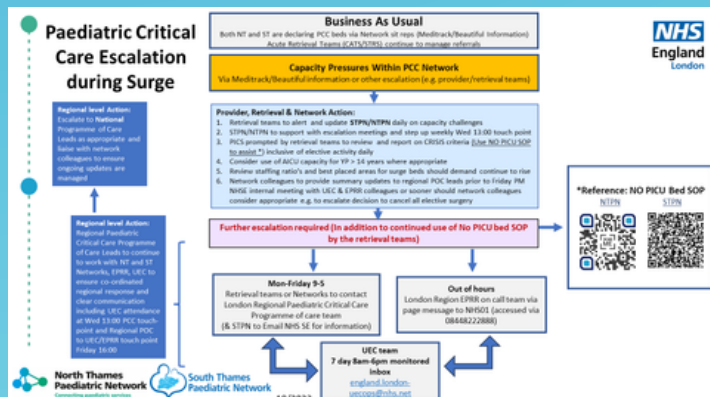
- The size of the demand/surge
- Capacity for paediatric patients across ICS regional footprints, London and England
- Workforce availability (Skilled workforce/staff sickness/staff burnout)
- The timing of the surge in relationship to other illnesses or specialty demand (e.g. CAMHS) that may peak in the UK over Winter.
- Cross-sector mutual aid
- Availability of necessary equipment/consumables

**North Thames
Paediatric Network**
Connecting paediatric services

The Network plays a pivotal role in supporting NHSE London Region and ICS partners with development of winter and/or surge plans for paediatric critical care

and specialty paediatric beds. In 2022/23 the Network worked together with the ICS to develop these plans and to interlink the local surge plans utilised for general paediatric beds by service providers and ICS sectors.

These have been further established through 23/24 and 24/25





WINTER & SURGE PLANNING

In addition to the overall surge plan, the Network produces updated advice and guidance for the treatment of patients with winter viruses (e.g. RSV/bronchiolitis) and long term ventilation patients. If there is a particular predicted area of infection concern (e.g. Strep A, Measles) then the Network will also work with clinical experts in the system and infection control teams to provide rapid guidance for sharing across the Network area.

LTV HUB

Access more Resources, Videos, E-learning and Competency Documents at LTV Central Team: ltycentral@nhs.net

Access Competency Documents for Tracheostomy and Tracheal Intubation with NTPN and NTPN: <https://www.npsa.nhs.uk/competency>

LTV Guidelines

MEDICAL EQUIPMENT USER GUIDES AND TROUBLESHOOTING

Astrot 150, Trintex 100, Trintex Eco, Nisus Junior 2, Nisus 4

CIRCUIT SET UP

Artemis 10, Stekar 100 & 150, NIV, Trache LTV

EDUCATION RESOURCES - VIDEOS

Respiratory Assessment, Mask fitting for NIV, Pressure sores & NIV, NIV Equipment troubleshooting, Securing a tracheostomy, Partially blocked Tracheostomy, Blocked Tracheostomy, BLS

Further information:
North Thames Paediatric Network: england.ntpn@nhs.net
South Thames Paediatric Network: england.stpn@nhs.net

Winter Surge Hub

V3 October 2023—Information was correct at time of printing. For review: September 2024

EDUCATION

Edith House Surge, Don't forget the bubbles, PCPP Modules, Edith Mental Health, NTPN Education

RESOURCES

GATS, LTV Hub, LTV Guideline, STOPP tool, Wellbeing

GUIDELINES

CPAP Guidelines, IPC Guidance, RCPCH Viral Res, HSE HET, PICU Stop Down policy

For further information please contact: North Thames Paediatric Network: england.ntpn@nhs.net

Measles Toolkit

Acute setting—For use by health professionals to support sharing of information
V1 September 2023—Information was correct at time of printing. For review: September 2024

Information for Health Professionals

National Guideline, Post Exposure Prophylaxis, Oral Fluid Test, Green Book, HPT

Information for Health Professionals

NICE Guideline, UKHSA Briefing Note Mar 2023, UKHSA Measles Fact Sheet

Information for YP

Think Measles

Information for Parents/Carers

NHS Poster, NHS Leaflet: Adults, Healthcare Together, NHS Page, UKHSA Posters

For further information please contact: North Thames Paediatric Network: england.ntpn@nhs.net

The Network also works to host additional education sessions ahead of Winter and ensure shared learning of resources e.g. in Children's Acute Mental Health (CAMHS)

NTPN Education and Resources (3/4)



Free NTPN Monthly Education sessions
<https://www.eventbrite.co.uk/e/north-thames-paediatric-network-clinical-forum-education-webinar-series-tickets-135519748215>

Children and Young People Mental Health – resources, guidelines, forums and education

Frameworks and Standards

CYP Mental Health Resources
https://docs.google.com/document/d/1Ztp2xvLA9W_Y8ANONeiQotNmK3ZK-W8/edit?usp=sharing&ouid=109468467138659762106&rtfpof=true&sd=true

Long Term Ventilation
in
Children and Young People
Clinical Guideline

Long Term Ventilation guidance,
resources and education

In response to rising cases of Mpox the network developed a highlight infectious toolkit.

Could it be Highly Infectious? Paediatric HCID Toolkit

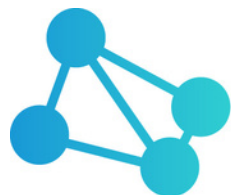
High Consequence Infectious Diseases
For unusual febrile illness in a child

Your Step by Step Guide with QR Code Guideline Links.

1. Travel History - for the patient and all household members.
2. Isolate the patient and family in a cubicle.
3. Call for Advice - Paediatric Infectious Diseases +/- Imported Fever Service
4. Wear appropriate protective clothing (PPE) (Mask, gloves, apron, eye protection)
5. Contact tracing - keep a record of who enters the room
6. Send appropriate microbiological samples (as advised)

SCAN QR CODES BELOW FOR FURTHER GUIDANCE

Fever in Returning Traveller	Gov.UK HCID Country Advice	NHSE PPE Donning	MPox UKHSA Guidance	Travel History Guide
Gov. UK Imported Fever Service	Gov.UK HCID Guidance	NHSE PPE Doffing	MPox NHSE Guidance	Contact your local Paeds ID team; St Marys Mon-Fri 9-5pm 07823536575 GOSH via: 020 7405 9200



MARTHA'S RULE PAEDIATRIC NETWORK PILOT SITE

The Network was successful in being appointed as one of three national pilot sites for a network level paediatric pilot. To support the pilot, pilot funding was received. The Network has established an expert Martha's team with clinical representation from both tertiary specialist paediatric care and the secondary district general hospital setting. In addition, to best support patients, their families and staff, the Network has appointed three paediatric nurses, all with specialist expertise who are taking on a role as patient/parent/family liaison nurses.

Martha's Rule is an NHS England initiative that has been developed in response to the death of Martha Mills and other cases related to the management of deterioration. Central to Martha's Rule is the right for patients, families and carers to request a rapid review if they are worried that they or their loved one's condition is getting worse and their concerns are not being responded to. The Network pilot aims to focus on identifying paediatric nuances to the pilot, in order to ensure that patients/parents/carers or staff are able to access a separate team review where requested and that patients and parents voices are heard. The pilot will continue through 2025/26 and the full report will be available for sharing then.] A clinical fellow will join the team in Autumn 2025 to assist with collating metrics and shared learning.

We Want to hear from you!

We want to hear your views about our service. Maybe you requested a Martha-CARE call, or were part of one, whatever your experience we will be reaching out for feedback.

Meet the NTPN Martha-CARE Team Consultants



Craig Knott Jenny Pallawela Beatrice Allnutt Javier Gavela

Family Support Nurses



Kylie Lyons Anne Dowson Annie Bruce

How can I find out more information?

Martha-CARE email address - NTPNMarthaCareTeam@gosh.nhs.uk
NHS England - <https://www.england.nhs.uk/patient-safety/marthas-rule/>

NTPN - Martha's Rule <https://ntpn.co.uk/marthas-rule-2/>
CATS - <https://cats.nhs.uk/wp-content/uploads/Family-Initiated-Referral-Guideline-CATS-28042025-Final-hotline.pdf>



**North Thames
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North Thames Paediatric Network Martha's Rule Pilot



Information for Staff





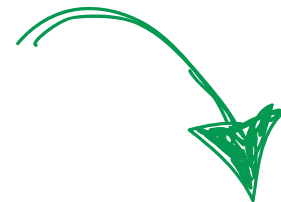
EDUCATION & SHARED LEARNING

Key Achievements 2024/25

Kimberley and Patrick joined the network education team, bringing a wealth of experience. This has enabled the education team to increase the education we provide. In 2024-25 the Network delivered education to nearly 6000 health care professionals.

Course	2024-25 Number of attendees
NTPN MDT Education Forum	Over 4000
NTPN Level 1 & 2 Course	87
Level 2 study days	28
Surgery Course	58
Pre-assessment Course	
Recovery Course	52
Neonatal Surgery course	580
Ad-Hoc Webinars	400

The Network launched its' Moodle website which gives the ability to develop e-learning packages to support learners whilst enrolled in courses.



Future Plans 2025/26

- Develop further courses: End of Life Study Day, Paediatric Anaesthetics Course and Senior Recovery Course.
- Expand the Moodle platform for all NTPN workstreams.
- Continued upskilling of level 2 centre staff, in line with on-going level 2 work across the network.



EDUCATION & SHARED LEARNING

Surgery in Children Education

- The Paediatric Recovery skills study day in collaboration with Great Ormond Street Hospital continued with expansion of the offering to different levels planned for 2025
- Neonatal Surgery study day – delivered in collaboration with three other networks yearly since 2023, this year continued to attract staff from across the country
- The Paediatric Pre-assessment practitioner course – 3rd cohort completed with 4th planned for 25/26.
- Paediatric Surgical Nursing course – 4 day course delivered in 2024, integrating both virtual and face to face session. With 3rd cohort starting in 2025. Presented at the RCN Education conference. Planning in place to propose a national roll out via the ODNs.
- Inclusion of development for play staff via an on line forum and face to face day

The Network Nurse Director, Tanya, and Education Lead Nurse, Amy, attended the Royal College of Nursing conference in Glasgow, where they presented on the educational initiatives implemented for nurses across the region aimed at enhancing the quality of care for surgical patients.

The Network team has also produced multiple essential information work sheets for use across hospitals.

Urinary Catheters: Essential Information

Indications

- **Urinary retention:** Inability to empty the bladder naturally.
- **Surgical procedures:** During and after surgery to monitor urine output.
- **Severe illness or injury:** When bedridden or unable to use the bathroom.
- **Chronic conditions:** Such as neurogenic bladder or severe incontinence.
- **Spinal Injury**

Things to Remember

- **Hygiene:** Keep the catheter and surrounding area clean to prevent infections
- **Hydration:** Drink plenty of fluids to ensure proper urine flow.
- **Regular checks:** Monitor for signs of infection or complications.
- **Proper handling:** Avoid pulling or tugging on the catheter.

Red Flags

- **Pain or discomfort:** Persistent pain or discomfort around the catheter site.
- **Blood in urine:** Visible blood or unusual colour changes in urine.
- **Fever or chills:** Signs of infection or Sepsis.
- **Leakage:** Urine leaking around the catheter.
- **Blockage:** Reduced or no urine output.





RISK AND GOVERNANCE



Dr Ruchi Sinha Clinical Lead

Consultant Paediatric
Intensivist
St Marys Hospital
National CRG Lead,
Paediatric Critical Care



Amy Hunter

Lead Nurse Paediatric
Critical Care, Education
Lead and Risk and
Governance Lead

55

INCIDENTS REPORTED ON NETTRACK

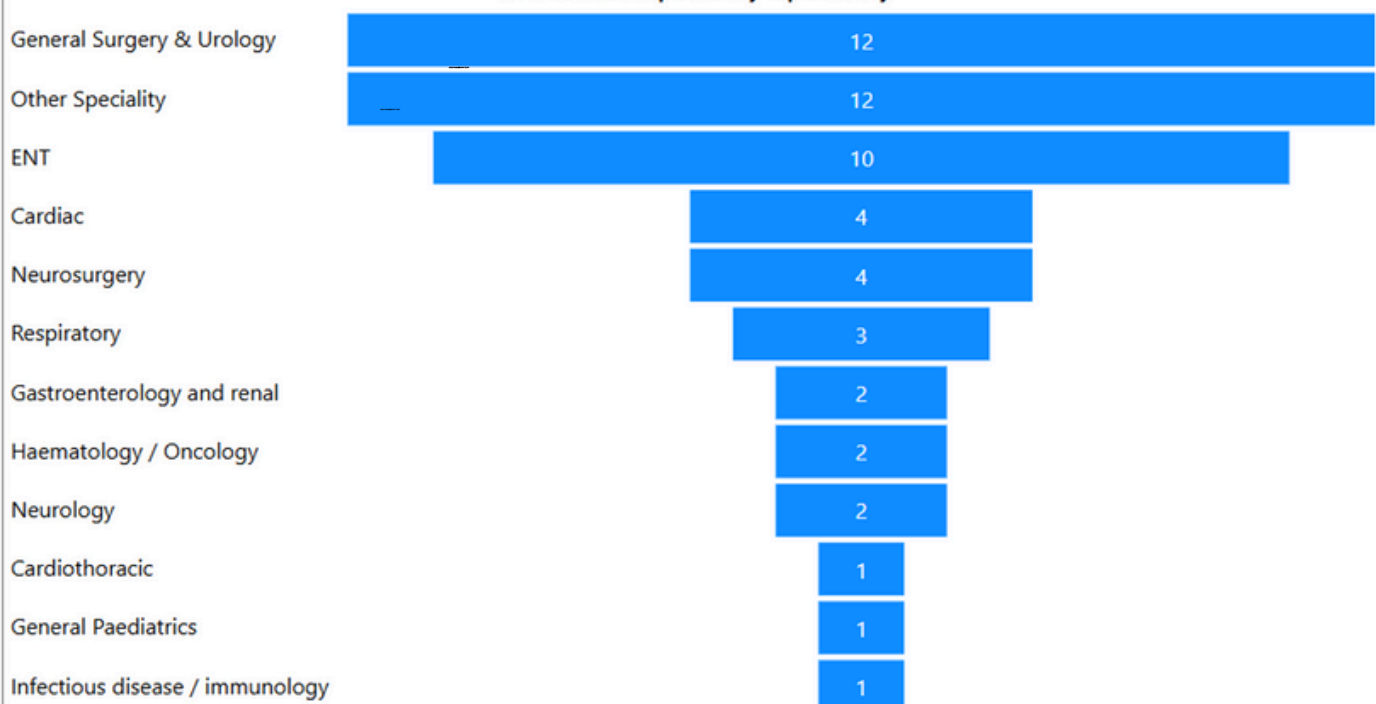
8

COLLABORATIVE MORBIDITY &
MORTALITY MEETINGS TOOK PLACE

5

EXPERT SPECIALITY LEVEL WORKSTREAMS
REVIEWING RISKS AND PATHWAYS ISSUES
ON NETWORK/MULTI SYSTEM LEVEL

Incidents Reports by Speciality





North Thames Surgery in Children ODN



Ms Ashwini Joshi
SIC Lead
Consultant
Paediatric Surgeon
Royal London
Hospital



Dr Shalini Bhatia
Anaesthetic Lead
Consultant
Paediatric
Anaesthetist
Barnet Hospital



Ms Nara Orban
Ear, Nose and Throat (ENT)
Lead
Consultant Paediatric ENT
Surgeon
Royal London Hospital

Key Achievements 2024/25

Surgical Pathways

The Network continues to support the use and establishment of safe, standardised, effective and efficient pathways for surgical patients across the network.

Escalation via Net Track, the Network's pathway risk and issues system and via the core team identifies where there are gaps. Where gaps are identified the Network has been able to assist in building the communication between surgical teams across the Network footprint to make recommendations and improvements.

Paediatric Spinal

The Network has contributed to the development of a Pan London shared Patient Tracking List that has been developed in more detail with the employment of a project manager based at the Royal National Orthopaedic Hospital

The level 2 / 3 work to review the HDU capacity has been completed and fed back to the spinal group.



Elective Recovery

The Network has undertaken visits to paediatric surgical providers within the Network footprint, with a particular focus on District General Hospitals. Site visits have given insight into the challenges faced by the different hospitals in the network and this alongside the previous self assessments has guided the development of education and support made available to our stakeholders for the coming year. This insight will be further utilised as the Network moves forward to play a more pivotal role in the redesign of paediatric emergency surgical pathways.

Monitoring Risk across Surgical and Ear, Nose and Throat pathways

The Network has been closely working with the Network Risk and Governance team, supporting the utilisation of Net track to highlight incidents across pathways and coordinate Network level M&Ms to disseminate learning.



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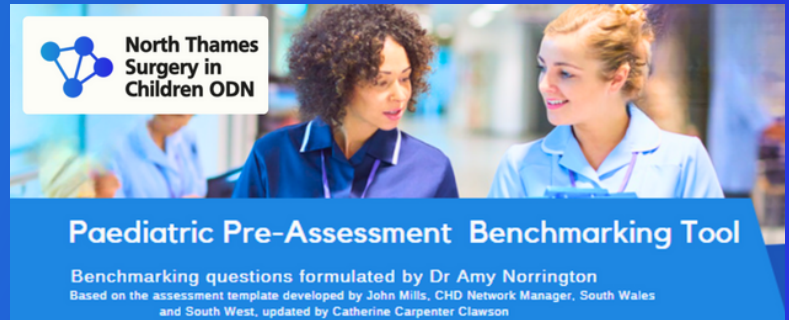


Key Achievements 2024/25 cont..

Button Battery Guideline

The Network has led on the development of a national guideline for children who have ingested button batteries.

The Network continues to chair the national group and is coordinating the gathering of ENT data to provide a background to the work.



The Network has been collaborating with other specialises surgery networks from across the country to develop education toolkits such as the Paediatric Pre-Assessment tool

Future Plans 2025/26

- Support the review and development of emergency and planned surgical pathways.
- Continue with peer review visits to all units providing surgical care to highlight areas of good practice and support those needing further development
- Integration of wider staff groups into the work of the network through regular forums.
- Review of acute paediatric orthopaedic provision.
- Develop education strategy to support AHP staff and other parts of the patient surgical journey.
- Review of preassessment provision at each trust with an intention to support development of services in line with national guidelines,

The Network has been part of a North Central London Clinical Reference Group developing future paediatric emergency surgical pathways. As the proposal passes through the consultation phase it is anticipated the Network will play a role in supporting by way of a centralised referral service and a roll out of education to ensure confidence in paediatric surgical skills



North Central London
Health and Care
Integrated Care System



North Thames
Paediatric Network
Connecting paediatric services

NHS
England
London



CARING FOR PAEDIATRIC SURGICAL PATIENTS - EDUCATION FOR NURSING STAFF TO IMPROVE QUALITY AND OUTCOMES

Authors:

Tanya O'Driscoll
Amy Hunter



**North Thames
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**North Thames
Surgery in
Children ODN**

BACKGROUND

The Surgery in Children Paediatric Operational Delivery Networks (ODN) were created to improve care for children and young people undergoing surgery following an NHS England review in 2019 and additional reports including GIRFT (2021).

As part of the development of the North Thames ODN we undertook a prospective review of current network paediatric surgical provision, including an assessment of skills and knowledge in relation to the services being provided. We were interested in the types of surgery being carried out and any gaps in knowledge or skills that had been identified by both the staff themselves and the leadership teams.

DEVELOPMENT

The outcome of the review highlighted the impact that Covid has had on the paediatric services across north London. As surgery was stopped completely in some hospitals, there are nurses that have not been exposed to surgical nursing care recently or have a very different experience of providing this care.

The main themes identified were a need for:

- Greater insight into the patient journey when admitted for emergency or elective surgery.
- Knowledge of the surgical procedures and how this may affect patient care post operatively.
- Understanding the different care needs of children with comorbidities such as asthma, diabetes, and haemoglobinopathies.
- Skills including post operative catheter care, wound care and dressings.
- Understanding and responding to surgical pain.

Cohort one was designed over 2 days, cohort 2 was increased to 4 days to cover more content. Cohort 3 (4 days) started in March 2023.



The biggest change in confidence score was noted for day 4 which was face to face and covered practical skills

All the knowledge and information I have gained throughout the course and the practical skills have helped me feel more confident in doing my every day nursing work

I have enjoyed the course as I have learned so much and it has boosted my confidence in caring for surgical patients.

I really enjoy the course. I've learnt so much from all the sessions over the 4 days and will now be able to help in my every day work which I can share with my colleagues.

COURSE OUTLINE

We collated the identified themes into a paediatric surgical nursing course. The course was split into four days with each day having a theme. Days 1 to 3 delivered virtually via Teams and Day 4 in person. All taught by subject matter experts from across the region.

- Day 1 – The patient journey.
- Day 2 – Common paediatric surgical procedures.
- Day 3 – Paediatric surgery and comorbidities.
- Day 4 – Pain management and practical skill stations.

Candidates ranged from band 4 to band 7



ACCESS

Although there are paid modules available that cover paediatric surgical nursing the aim of this programme was to be inclusive, ensuring that nurses both paediatric registered and adult registered but working in paediatrics would be able to access the learning and take away skills to improve practice in their hospital. Also ensuring resilience in the workforce and reducing variation of standards in education for staff across the region.

To ensure accessibility for all staff across the network we designed the course to be virtual for three days, with the fourth day in person at a central location. We opened the course up to non-registered staff working in paediatric areas and provided this course free of charge to ensure funding is not a barrier to accessing the course.

EVALUATION

Candidates were asked to provide feedback for each session via an online questionnaire, they were also asked to self assess their level of confidence prior to and post each day.

The results demonstrated candidates had gained insight into the patient journey, with greater understanding of the need for good communication and how this can improve the patient experience. The knowledge gained of surgical procedures and how this relates to the post operative care has led to better care provision and improved conversations with children, young people and their carers about the procedure and the aftercare.

Candidates have increased their confidence in caring for children with a range of comorbidities and with additional requirements which enables these children to be cared for closer to home.

RECOMMENDED READING

Paediatric critical care and surgery in children review, NHSE (2019)
Standards for Children's Surgery, Royal College of Surgeons (2013)
Paediatric General Surgery and Urology: National Specialty Report, GIRFT (2021)
Ear, Nose and Throat Surgery: National Specialty Report, GIRFT (2019)

ANAESTHETICS

This year the focus on educational projects has continued in the Network's anaesthetics workstream, with particular recognition of the need to support secondary care hospitals in the management of deteriorating children. This is an expected part of the workload of secondary care anaesthetists and/or intensive care doctors, however this is an infrequent event for most, whose focus of practice is likely to be adult medicine.



Study exploring knowledge, skills and experience in the management of deteriorating children using a 'Delphi' methodology:

An initial study showed evidence of variation in outcomes related to intubation in secondary care in North London and East of England (CATS transport region). The study was done on every intubated paediatric patient transported by the Children's Acute Transport Service (CATS) from June 2016 to May 2018 (over 1000 children) and found a higher rate of adverse tracheal intubation-associated events in non-specialist centres versus tertiary centres with PICU (22.7% versus 20%) and a significantly higher rate of severe events (3-6.5% in tertiary centres compared to 13.8% in local non-specialist hospitals).

Following this, the Network decided to set up a study that used a 'Delphi' methodology to explore this further by seeking the views of experienced consultant anaesthetists and intensivists who manage deteriorating children. The aim was to collate the outcomes of this study and develop a publication and/or model that could be deployed regionally or nationally to support training and development for anaesthetists and contribute to equity of care and the reduction of unwarranted variation. The 'Delphi' methodology was selected because this is the style of data collection best suited to situations where there is a lack of published evidence available. The Delphi process is a structured method of developing consensus amongst a panel of experts, involving free text submission of ideas in round one, development of statements that experts then rate as to the extent of their agreement in round two, and a final opportunity to see what others have said and amend their ratings in round 3, which can then inform the creation of a standardised model.

The Network sought to gain consensus on three domains related to learning, knowledge, skills, and experience. By March 2025, two out of three rounds of a Network 'Delphi' study had taken place, gaining views from 44 consultant colleagues across North Thames and East of England regions. The Network is preparing for the final round in April-May 2025, where as well as a final amendment of statement scores, experts can also indicate their preferred frequency of each proposed intervention.

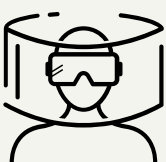
PAEDI pilot in partnership with Health Education England

The PAEDI (Paediatric Anaesthesia Emergency Department Initiative) project pilot ended this financial year and the results have been analysed and presented. PAEDI is a collaborative project between Health Education England and the North Thames Paediatric Network. The main objective was to provide dedicated clinical training for anaesthetic trainees, CESR and Trust grade doctors in the most common paediatric disease entities requiring intubation and retrieval. The project was piloted from April 2022 to April 2024 within North Middlesex and Queen's Romford Emergency Departments.

The achievement of the pilot objectives was measured using feedback surveys, which were completed by each trainee pre- and post-pilot to capture confidence levels in the management of common conditions and deteriorating children before and after this targeted intervention. The results were impressive; for most competencies, the median level of confidence significantly increased. Participants did not report increased confidence in some areas such as cardiac arrest, which may reflect a lack of exposure during the pilot period. A general finding is that those who were more invested in the pilot and could see the value of the training seemed to gain more benefit from their participation. The project is now seeking further funding to continue the work and roll out more widely, and the results have been presented to Health Education England and NHS England.


Health Education England

VR and Simulation training



The Network ran a virtual reality training session in July 2024. This was a successful day and it provided colleagues with realistic scenarios in the management of deteriorating children and allowed trainees to get involved and receive feedback from consultant colleagues. VR videos of the session were created as a learning resource, supported by VRiMS (Virtual Reality in Medicine & Surgery).

Healthcare Play



In 2024 the North Thames Paediatric Network carried out visits to our acute care providers. We assessed the provision of play for children and young people and what support is in place for staff who work in this area and found that there is a significant variation in play provision across the different healthcare settings, and availability funding for resources. The Network identified that accessibility for further training post registration to support and develop staff varies dependant on where the post holder works.

The Network has subsequently set up a healthcare play forum for staff to obtain support and advice from their co-workers in the region and held a face-to-face event for play staff which took place in September 2024, The Network will continue to work with play teams. The aim is to develop a collaborative approach to supporting health play staff in developing their services and ensuring a combined voice for health play across the sector.



Healthcare Play Transfer document

One outcome from the in-person meeting held in September 2024 was the acknowledgement that play specialists should have access to a document containing essential information about the care of children or young people being transferred to another hospital in the region. This document has now been approved by the group and is available for use by all play specialists in the North Thames area. This document can be accessed via our website

<https://ntpn.co.uk/healthcare-play/>

The team presented their work for play specialists along with Society of Health Play Specialists (SoHPS) at RCPCCH conference in 2025 (see overleaf)



**North Thames
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NHS
England
London

SUPPORTING AND DEVELOPING THE HEALTH PLAY WORKFORCE ACROSS NORTH THAMES PAEDIATRIC NETWORK



**North Thames
Paediatric Network**
Connecting paediatric services

Authors:



SoHPS
Society of Health Play Specialists
<https://sohps.org.uk>

Tanya O'Driscoll, Nurse Director NTPN

Irene O'Donnell - Play and Youth Lead UCLH
SoHPS workforce lead

INTRODUCTION

The NTPN carried out visits to North Thames acute care providers (2023/24) to seek out areas of good practice and areas for development. Part of this review assessed the provision of play for children and young people, as well as the support and development in place for staff in these teams.

We were interested in the wellbeing of staff in health play roles and in evaluating how the NTPN core team can contribute to this. With this data we aimed to develop a collaborative approach to supporting health play staff in developing their services and ensuring a combined voice for health play across the sector.

METHOD

We undertook a prospective review of the current health play cover across different providers within the North Thames Paediatric Network (NTPN) to assess how the numbers and skill mix relate to the service being provided. Play staff and paediatric management teams were asked about the current level of play provision and the expectations of staff in terms of tasks and the number and acuity of areas needing to be covered. A survey was distributed by google forms to all play teams across the acute trusts to assess play staff views on the support they need. This was augmented with discussions with senior play team leads across the network as to current availability of training and support.



REFERENCE

A Common Purpose. Report of the Taskforce on Children's Play in Healthcare (2023)

Supported by:
Jessica Kinghorn (NTPN)
Starlight Children's Foundation

RESULTS

We found that there is significant variation in play provision across the different settings and also within wellbeing support and development available for staff.

We identified that accessibility to further training post registration varies considerably dependent on the setting in which the post holder works, with established programmes being available within larger tertiary centres, and minimal availability to post holders in other providers.

CONCLUSIONS

Health Play staff now work in a variety of settings including acute trusts, tertiary centres, hospices, and community. Recent work (1) has reviewed the health play workforce and generated recommendations at national level to support staff both in job titles, grading, and levels of responsibility, but additional local support will be needed to take this forward.

Wellbeing of staff is pivotal to the development of health play teams and the NTPN can work with providers to champion and facilitate this.

ACTIONS

Having identified that provision of additional support for this group of staff as well as creating a shared ownership of play services is needed at a local level we facilitated a collaborative team day, bringing over 40 play staff from across different providers together with representatives of the play taskforce and the Society of Health Play Specialists. Issues raised centred around development of play staff and recognising current barriers to play provision, including recognition of the role, and the ability of teams to communicate between provider settings. We have also engaged with SoHPS representatives to ensure staff receive regular updates and can access support.

FUTURE PLANS

Continue to facilitate communication through regular forums, facilitating accessibility to shared documents via our website and highlighting the benefits of health play at all levels.

Collaborate further with SoHPS and other health play related organisations to ensure support and development of healthcare play staff across the network



SCAN ME



North Thames Paediatric Cancer Network



Dr Lynne Riley
Clinical Director
Consultant
Paediatrician
Haem/Oncology
Great Ormond Street
Hospital for Children



Dr Jeremy Roskin
Clinical Lead
POSCU
Consultant Paediatrician
Watford Hospital



**Dr Richa
Ajitsaria**
Clinical Lead
POSCU
Consultant
Paediatrician
Hillingdon Hospital



Emily Baker
Joint Nurse Lead PTC
Senior Clinical
Research Nurse



Rochelle Lowe
Joint Nurse Lead PTC
Advanced Nurse Practitioner



**Lucy
Simons**
Nurse Lead
POSCU
Nurse Specialist

The Paediatric Cancer national service specifications were published in 2021 and our ongoing work focuses largely on the delivery of these, in particular working with our Paediatric Oncology Shared Care Units (POSCUs) in meeting the Enhanced Level A requirements.

POSCU Transformation Project - 2024/25 Key Updates

- This year, our work towards implementation of the POSCU service specifications continued. Following the development of Network recommendations for workforce to clarify key aspects of the specifications, and the analysis of gaps against these recommendations at each POSCU, we worked with NHS England to share these with POSCUs and ICBs and gain support to take this work forward.
- We have been working with POSCUs in North London to submit Service Development & Improvement Plans for review with ICB colleagues. A proposal was taken to the commissioner costing committee to secure agreement to prioritise this work and allocate funds to support POSCUs in putting appropriate staffing in place to deliver Monday to Friday infusional chemotherapy. We have already had some successes with this and in one ICB area £400,000 has been allocated and work is in progress to allocate this spending to staff groups across their three POSCUs.

CCLG-funded infusional chemotherapy training pilot

- In line with our POSCU transformation work, we launched our infusional chemotherapy education & training pilot, utilising funding from CCLG to employ Dr Jennifer Ho as our new clinical fellow to lead on this work. This pilot is run jointly with South Thames and aims to train staff from POSCUs aiming to become an Enhanced Level A in the delivery of infusional chemotherapy (starting with cyclophosphamide and doxorubicin) and associated supportive care drugs. The content will have a theoretical component on CCLG's Moodle platform, and a practical component, with the initial pilot training day planned for 28th November 2025.
- Four pilot sites (two from North Thames, two from South Thames) will be selected in the first instance via an expression of interest process. Training modules are in the process of being developed for Moodle by the Network teams.

POSCU transformation poster presented at CCLG Conference 2025

DEVELOPING RECOMMENDATIONS TO SUPPORT COMMISSIONING OF ENHANCED LEVEL A POSCUs: A PAN-THAMES APPROACH

Lynne Riley, Anne Davidson, Richa Ajitsaria, Jeremy Roskin, Donna Townsend, Emily Baker, Rochelle Lowe, Lucy Simons, Tracey Crowe, Rupal Evans, Pritesh Patel, Lamia Samrin, Louise Henry, Gemma Renshaw, Jason Tong, Lauren Martin, Pia Fagelman, Emily Goss, Rachel Lundy, Julia Chisholm



North Thames Paediatric Cancer Network



GLOSSARY

AHP - Allied Health Professional
ELA/B - Enhanced Level A/Level B
ODN - Operational Delivery Network
POSCU - Paediatric Oncology Shared Care Unit
PTC - Principal Treatment Centre
SACT - Systematic Anti-Cancer Therapy
SL - Standard Level
T&F - Task & Finish

1. INTRODUCTION

A POSCU benchmarking exercise in 2022 by North and South Thames Children's ODNs highlighted significant gaps in service provision against NHS England's Enhanced Level A POSCU service specifications (November 2021) and the need for specific interpretation of some aspects to support the regional service model. To inform future commissioning, the North and South Thames ODNs worked jointly with NHSE Specialist Commissioners to: 1) Identify current POSCU gaps, risks & mitigations, 2) Develop specific recommendations for safe delivery of excellent, equitable, local care, including enhanced SACT services, and 3) Identify priority areas for designation of ELA POSCUs.

2. METHODS

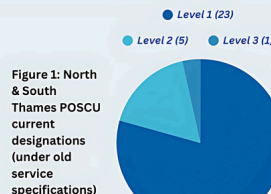
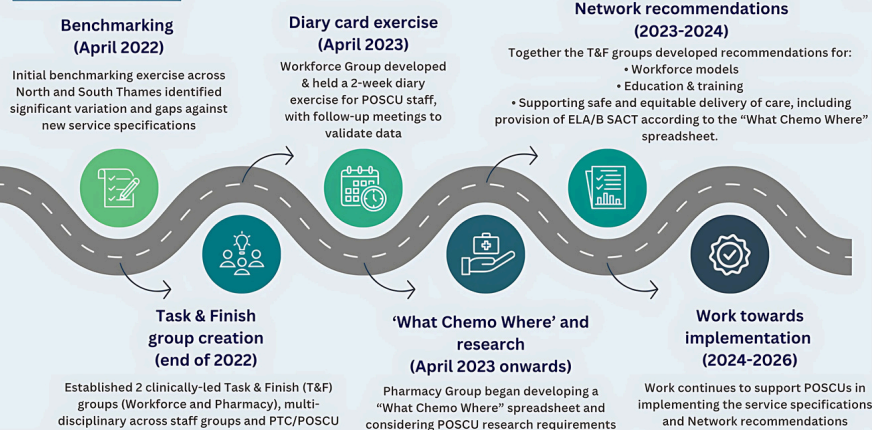


Figure 2: North & South Thames POSCU 'ambition' (desired future designation level under new service specifications)

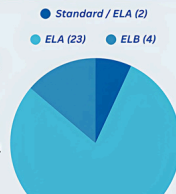
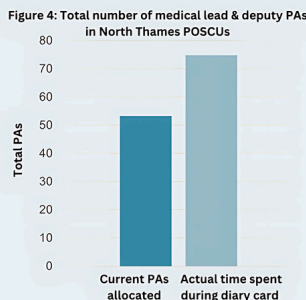
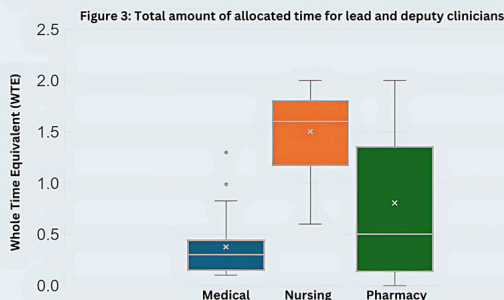


Table 1: Example of the POSCU diary card exercise

Clinical Service - direct clinical care and management							
Where questions ask about time, please express total time in minutes for the following work: For all of the below, please complete for each individual POSCU clinician (Lead or Deputy) during this diary period. Please include time spent completing associated admin - notes, clinic letters etc.							
Chemotherapy delivery							
Week One	Monday 4/17/2023	Tuesday 4/18/2023	Wednesday 4/19/2023	Thursday 4/20/2023	Friday 4/21/2023	Saturday 4/22/2023	Sunday 4/23/2023
Total number of patients seen for chemotherapy (mins)	0	0	0	1	0	0	0
Time spent chemotherapy prescribing for patients (trial and non trial) (mins)	0	0	0	40	0	0	0
Medical time spent with or being available for patients attending for chemotherapy (mins)	0	0	0	30	0	0	0
Week Two	Monday 4/24/2023	Tuesday 4/25/2023	Wednesday 4/26/2023	Thursday 4/27/2023	Friday 4/28/2023	Saturday 4/29/2023	Sunday 4/30/2023
Total number of patients seen for chemotherapy (mins)	0	0	0	1	1	0	0
Time spent chemotherapy prescribing for patients (trial and non trial) (mins)	0	0	0	0	0	0	0
Medical time spent with or being available for patients attending for chemotherapy (mins)	0	0	0	45	60	0	0

3. RESULTS

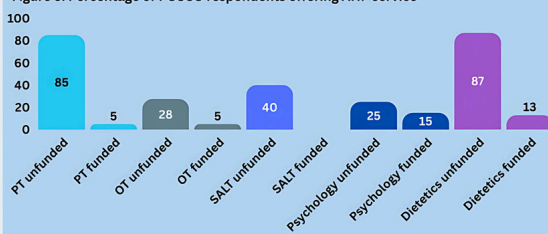
Work from the T&F groups demonstrated wide variation in workforce and Monday-Friday SACT provision in current care models. Figure 3 shows this variation between POSCUs in their medical, nursing and pharmacy lead and deputy staff time, with the size of the box (interquartile range) correlating with the level of sample dispersion. Figure 4 shows the discrepancy between job planned time for medical leads and deputies and the actual time that they reported spending on POSCU work through the diary card exercise in North Thames POSCUs. Across all staff groups in both North and South Thames, reported work time was higher than job planned time, highlighting the overstretched staffing and reliance on 'good will', even at current level of service provision.



3.1 AHP & PSYCHOLOGY WORKFORCE

To gather data on current service provision, dietitians, physiotherapists, occupational therapists, speech and language therapists and psychologists working in pan-Thames POSCUs and PTCs were contacted by telephone or email and asked questions about their services, workforce and waiting times. Perceived AHP and psychology access was also asked of nursing colleagues, and perceived versus actual provision was compared. Working groups were subsequently run to generate input into future service plans.

Figure 5: Percentage of POSCU respondents offering AHP service



3.2 KEY PRIORITIES

The North & South Thames Children's Cancer ODNs recommended five key priorities imperative to the delivery of consistent care closer to home.



3.3 NETWORK RECOMMENDATIONS

Table 2: Network recommendations for ELA medical, nursing and pharmacy lead and deputies

Medical	Nursing	Pharmacy
6.5 PAs in total, split across lead and deputy/s - includes: 5 clinical PAs 1.5 leadership, education and training PAs - Plus an additional 1 PA for every 5 new patients per year over an average of 15.	2 WTE in total, split across lead and deputy/s - includes: 0.2 WTE for educational activities 0.1 Nurse Trainer role (if named Nurse Trainer is the lead or deputy) - Plus an additional 0.2 WTE for every 5 new patients per year over an average of 15. - There must be at least 2 fully trained nurses on shift to administer chemotherapy, excluding lead nurse.	0.5 WTE (2.5 days) in total, split across lead and deputy/s, with a minimum of 0.4 WTE allocated to the lead. Must be across all working days. - Plus an additional 0.3 WTE for every 5 new patients per year over an average of 15. - Lead to be a minimum Band 8a. Deputy to be a minimum Band 7. - There must also be an additional Band 7 pharmacist(s) allocated at least 0.7 WTE, across all working days.

4. CONCLUSIONS

This work clarifies information in the service specifications to enable consistency in access and delivery of ELA POSCU care across the region. It provides clear recommendations for planning future workforce and education/training needs for safe SACT delivery. POSCUs are now being provided with a provisional designation subject to agreement of co-produced implementation plans that support the five key priorities, working towards full compliance by Autumn 2026. Implementation will be supported by a pan-Thames ODN education pilot that will deliver training to selected POSCUs in the delivery of certain infusional SACT agents, as defined by the 'What Chemo Where' work, starting with cyclophosphamide and doxorubicin. AHP workforce will need further consideration regarding POSCU recommendations as work progresses.

3.4 'WHAT CHEMO WHERE'

Priority Level Assigned	Designated Level of Unit able to Administer Named Drug	Drug Name	Drug Route: Oral (PO) Intra-Venous (IV) Intrathecal (IT) Intra-Muscular (IM)	Dose
ENHANCED A POSCU				
2	Level A Enhanced	Actinomycin	IV	Bolus
1	Level A Enhanced	Cyclophosphamide	PO	
1	Level A Enhanced	Cyclophosphamide	IV	Infusion <1g/m2
1	Level A Enhanced	Cytarabine	IV	Low Dose Bolus <100mg/m2
1	Level A Enhanced	Damunobin	IV	Infusion
1	Level A Enhanced	Dexamethasone	PO	
1	Level A Enhanced	Doxorubicin	IV	Infusion
1	Level A Enhanced	Erwinase	IM	
1	Level A Enhanced		IV	

The Pharmacy sub-group 'What Chemo Where' spreadsheet aimed to establish guidance and a roadmap for daycase bolus and infusional chemotherapy agents to be given at POSCUs. They reviewed the approved regimens lists in North and South Thames ODNs to create a comprehensive pan-Thames list that defined which SACT can be given at Enhanced A and B POSCUs after designation.

CONTACTS

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Dr Julia Chisholm (South Thames) - julia.chisholm@nhs.uk

Cytarabine administration theory training for community nurses



NHS
England
London

- We identified a need for SACT training focused exclusively on cytarabine administration and specific to Children's Community Nurses (CCNs), who do not need to attend the current full courses provided by PTCs. The full courses are very comprehensive and include information not relevant to CCNs, are mostly face-to-face and incur a cost. The PTCs also cannot support with marking and sign-off of SACT passports for external organisations. The ODN sought to address this gap by offering free virtual training and passport sign-off for CCNs who administer cytarabine.
- The ODN nurses held four sessions and collected feedback from attendees. Evaluation responses were extremely positive. The ODN will continue to run these sessions for community teams throughout the next financial year. The ODN also presented this work as a poster at the CCLG conference 2025 (next page).



28 cases flagged between April 2023 and April 2025

12 cases presented at M&M meetings



1 clinical debrief

9 learning summaries shared with stakeholders



35 attendees at our April 2025 M&M meeting
56 attendees at our January 2025 M&M meeting



Examples of cases investigated via our risk and governance processes

Case 2:

- Issue: Vincristine dose given twice at PTC and POSCU, additional similar near miss incident
- Action: Established process for robust communication of SACT administered at POSCU
- Outcome: In a recent audit, notification of SACT increased from ~50% -> 100%

Risk & Governance

- Our risk and governance work in the paediatric cancer team, lead by Dr Richa Ajitsaria, has continued to excel with regular Morbidity & Mortality (M&M) meetings throughout the year. The infographic on the left shows some of the highlights of our risk and governance programme.
- The success of this workstream has led to the development of a Network risk and governance policy based on the paediatric cancer team's work

Example extract from Network risk policy

North Thames
Paediatric Network
Connecting paediatric services

4 Incident Reporting and Management

4.1 Responsibilities

- **Trust-Level Investigations**
 - Responsibility for investigating incidents lies with the individual trust(s) involved. Each trust must ensure rigorous and timely reviews to identify root causes and implement corrective actions.
 - Incidents must be submitted by a senior local clinician, including the trust's Datix ID, to ensure accurate tracking and accountability.
 - Cases at individual Trusts where there is benefit to sharing the learning more widely between Trusts should be discussed with the Risk clinical lead as to how this can be enabled.
- **Network Pathway Issues**
 - Issues, risks and incidents identified at the Network level must be reported via NetTrack, which serves as the central repository for incident tracking and resolution.

Case 1:

- Issue: Death of child with ALL in induction from systemic HSV
- Action: Increase awareness of early testing/treatment of HSV with risk factors/signs
- Outcome: Pan-London Supportive Care Protocol amended and circulated

Cytarabine training poster presented at CCLG Conference 2025



**North Thames
Paediatric Cancer
Network**

CYTARABINE ADMINISTRATION THEORY TRAINING FOR CHILDREN'S COMMUNITY NURSES: A PILOT STUDY

GLOSSARY

CCN - Children's Community Nurses
ODN - Operational Delivery Network

POSCU - Paediatric Oncology Shared Care Units
PTC - Principal Treatment Centre
SACT - Systemic Anti-Cancer Treatment

AUTHORS

Emily Baker and Lucy Simons (Lead Nurses)
North Thames Children's Cancer Operational Delivery Network (ODN)

SPECIAL THANKS

Jessica Kinghorn (Junior Project Manager)
North Thames Paediatric Network

INTRODUCTION

The North Thames Children's Cancer ODN identified a need for SACT training focused exclusively on cytarabine administration and specific to Children's Community Nurses (CCNs), who do not need to attend the current full courses provided by PTCs. The full courses are very comprehensive and include information not relevant to CCNs, are mostly face-to-face and incur a cost. The PTCs also cannot support with marking and sign-off of SACT passports for external organisations. The ODN sought to address this gap by offering free virtual training and passport sign-off for CCNs who administer cytarabine.

AIMS

- To assess if offering a free virtual half-day training course would provide the theoretical knowledge required to complete the CCN-specific sections of the SACT passport
- To ascertain if staff already competent in cytarabine administration would be willing to complete the SACT passport in order to sign off their team members in the future
- To assess the feasibility of the ODN lead nurses marking and signing off the SACT passports until sufficient staff are trained locally to take on this role

METHODOLOGY

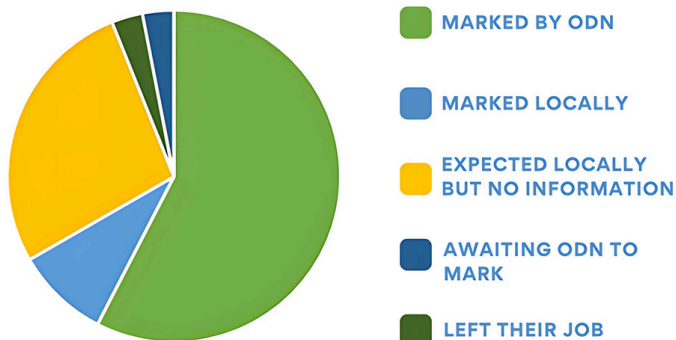
The theory content was mapped to the CCN sections of the SACT passport, alongside key issues for cytarabine and home administration. The ODN nurses held four sessions and collected feedback from attendees. Names and teams of attendees were recorded and SACT passport completion was tracked. A follow-up survey was sent to those who had attended the first two sessions (the third and fourth session attendees will receive this at a later date).

RESULTS/FINDINGS

Total number of staff that attended across the four dates: 43	Number of community teams who have sent staff: 14
Number of participants (response rate to evaluations): December 2023- 12 (100%) April 2024- 12 (60%) September 2024- 8 (88%) January 2025- 11 (64%)	Percentage of participants that felt they were appropriately prepared to complete the SACT passport: December 2023 - 100% April 2024 - 100% September 2024 - 86% January 2025 - 100%
Number of community teams now able to mark and sign off their own staff: 8 (in addition, 2 POSCU CNSs can now sign off their own staff, having had their Enhanced level passport marked by the ODN)	

"It was great to hear what other teams are doing... I can bring new information back to the team... so pleased to have something tailored to CCNs"

SACT PASSPORTS MARKED



CHALLENGES

- The CCNs found it difficult to find time to complete SACT passports.
- It was time-consuming for the ODN to follow up with staff across multiple teams to capture accurate completion of the SACT passports.

NEXT STEPS

- The ODN will continue to offer the free virtual training to CCNs
- The ODN will aim for all CCN teams to have at least one person within their teams who is able to mark and sign off SACT passports
- The ODN will review the provision of SACT updates and whether any further support can be offered
- The ODN will develop further training specific to CCNs

CONCLUSION

- The free virtual training sessions run by the ODN received extremely positive evaluation responses, and were an achievable way to provide training to a wide geographical area, including as a refresher or annual update.
- Existing chemotherapy competent staff were willing to complete the SACT passport or to evidence previous competency in order to take on marking and sign-off.
- Although tracking completion of SACT passports was time-consuming, it is possible for the ODN to support teaching and SACT passport sign-off for CCNs.
- This evidences a sustainable model for the future of local marking and sign-off (in January 2025, only 2 people required ODN marking, as all other attendees had a local staff member to provide this).



Work to improve GOSH Link (Epic)

There is ongoing work to increase/improve functionality of GOSH Link (i.e. the interface web-based read-only system for POSCUs to log into GOSH/UCLH Epic and improve digital communication, thereby improving patient safety. 100% North Thames POSCU teams now have access to GOSH Link. The clinical director presented at the 2025 Epic conference and her work was highly praised.

Systemic Anti-Cancer Therapy (SACT) Passport

The Network lead nurses devised a SACT passport marking guide for CCNs and POSCUs which was agreed across both North and South Thames to help with answering questions around who needs to complete and who can mark this new document. This was sent out in Feb 2025.

Priorities for 2025/26

Theme	Planned work
POSCU Transformation work - Implementation	•Continue to support POSCUs in working towards Enhanced Level A specification requirements •Continue to work with ICBs and NHS England to secure funding for additional staffing needs and service redesign, and work with POSCUs to get implementation plans in place
POSCU Transformation work – Education & training	•Develop multiprofessional training resources and implement a multidisciplinary education pilot to aid existing Level 1 POSCUs to upskill and deliver infusional daycare chemotherapy locally (initial focus will be on doxorubicin and cyclophosphamide) •Review the pilot and roll out the education and training programme more widely to all Enhanced Level A POSCUs. Resources will then be available nationally via CCLG platform.
Risk and governance	•Continue risk and governance work, including regular Morbidity & Mortality (M&M) reviews of Network-level risks. Ratification and dissemination of risk and governance SOP. Risk reporting via NetTrack from across the Network - learning shared through summaries.
Cytarabine training for community nurses	•Continue to offer free virtual cytarabine administration training and passport sign-off specific to Children's Community Nurses (CCNs)
Pentamidine	•Plan to support more POSCUs to deliver Pentamidine (supportive care drug) locally rather than at GOSH
Transition pathways from GOSH to UCLH for haematology and oncology patients	•Complete quantitative review of the numbers of patients aged 13 and over currently being looked after by haematology and oncology teams in acute clinics both on-treatment and off-treatment (consultant and diagnostic level data) •Present findings to the GOSH haematology and oncology teams to assess and discuss scale of current transition pathway problems and establish potential solutions/pathways
Improve communication between PTC and POSCU via Epic	•Continue to work with the GOSH Epic team to improve communication and recording of patient information through the GOSH Link Interoperability function. Optimise functionality, including supporting POSCUs to use it to maximum efficiency, uploading documents directly and developing enhanced functionality for POSCUs



North Thames Teenage and Young Adult Cancer Network



Dr Ben Carpenter
Clinical Director
Consultant
Haem/Oncology
University College
London Hospitals



Dr Elinor Sefi
Clinical Lead -
Transition
Consultant
Paediatrician
Whittington Hospital



**Lisa-Marie
McMonagle**
Lead Nurse
Nurse Consultant
University College
London Hospitals

The Teenage and Young Adult Cancer national service specifications were published in May 2023 so our ongoing work focuses on delivery of the ODN and Principal Treatment Centre (PTC) specifications, and supporting the Designated Hospitals in implementing their specifications.

Data and MDT

Gathering data on where young people choose to receive care, and ensuring referral to TYA cancer MDT



Clinical Nurse Specialists

We have increased the Clinical Nurse Specialists through Teenage Cancer Trust charity funding.

DH specifications

Working with hospitals to ensure there is a TYA cancer link clinical lead and nurse within each service and bringing stakeholders together



Website and padlet

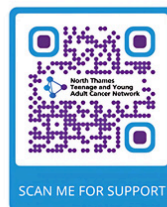
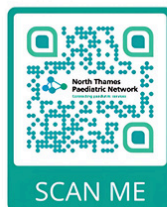
As part of our new NTPN website, we have included a number of patient and professional resources. We have also developed a Padlet with helpful links for sites to disseminate.

Education

We have set up oncology teaching sessions on Thursday mornings. We plan to develop further teaching on Moodle.



Current Network projects



Non-specific symptoms

Working with North Middlesex to expand their rapid diagnostic clinic for non-specific symptoms, so that 16 and 17 year olds are also included..

Long term follow up

Work to understand gaps in long term follow up care and possible solutions



Rapid access lymph node clinic

Rapid access lymph node diagnostic clinic at UCLH – ultrasound and biopsy – for all TYA

Psychology & youth work

Developing a psychology and youth work model and introducing a Youth Support Coordinator to support 100+ young people being cared for outside of UCLH



Genomics, tissue banking & trials

Introducing a Genomics, Tissue Banking & Clinical Trials facilitator to improve access to whole genome sequencing, sample collecting and banking, and clinical trials. We now have whole genome sequencing samples being sent out of UCLH (also pathway mapping and education work)

NHS
University College London Hospitals
NHS Foundation Trust

Teenage and Young Adult Cancer Services
University College London Hospitals NHS Foundation Trust
235 Euston Road, London NW1 2BU

020 3447 9950
uclh.cypcsadmin.team@nhs.net



Please scan the QR code for useful information and resources that can help to support you during your care and beyond

Education, Webpage & Padlet

- The team have developed a webpage of resources for patients/families and professionals. Patients are able to access information in relation to, Clinical Trials, Mental Health, Tissue Banking, whole genome sequencing and eating well during cancer treatment.
- The team have also created an extensive Padlet resource page for patients which can be accessed via a QR code. This code was then placed on a business card so it is easy for professionals to hand out during clinic (replacing the current paper information packs)
- The team also continue to run **weekly oncology education sessions**, highly valued by clinicians across the Network, which are then uploaded to the 'professionals login only' side of the website for future access.

TYA patient audit (designated and non-designated hospitals)

- One of the criteria of the national TYA cancer service specifications published in May 2023 is that all TYA cancer patients must be reviewed at the Principal Treatment Centre TYA MDT (at UCLH) and we are keen to get a better understanding of the total TYA cancer population and what proportion of patients are currently being referred so we can work to improve this, offer additional support and ensure care is coordinated.
- There is currently no way of easily obtaining this data through standard reporting, so we ran an audit looking at the number of young people diagnosed with cancer across the region. We asked all centres within the North Thames region, both designated and non-designated hospital sites, for their TYA patient numbers. The inclusion fields were 1) aged 16-24 at time of diagnosis 2) diagnosed with a new malignancy between 1st July 2023 and 1st July 2024. We also requested more recent data where this was accessible.
- We had responses from 11 sites, with an additional response pending, including non-designated hospitals, and this has helped to enrich our understanding of where patients are being seen across the region so we can reach out to these centres, and also has given us a clearer view of the proportion of patients currently being referred to the TYA psycho-social MDT at UCLH. In 2025/26 we will use this information to develop further plans to improve compliance with this metric in the region and embed universal support offer.

16 - 17 year old Non-Specific Symptom (NSS) Clinic

This year, we developed our plans for a pilot project to extend referrals to the North Middlesex Rapid Diagnostic Centre (RDC) to include patients aged 16-17 years old with non-specific symptoms, such as recent onset fatigue, unexplained weight loss and abdominal pain where there is a suspicion that it could be cancer. Previously the RDC only saw patients over the age of 18, however younger patients aged 16-17 experience a significant diagnostic gap and delays in review, so we are now encouraging our GP colleagues to refer any 16-17 year old patients with non-specific symptoms (or where GP has a 'gut feeling' that it could be cancer) so that cancer can be excluded and patients directed to appropriate onwards support. NTPN is funding 1PA of paediatrician time to input into review of the 16-17 year old patients, as a 12-month pilot. If the outcomes of the pilot are positive, we hope that the service will become embedded as 'over 16s' longer term. We are hoping to work with other RDCs in future to lower the age cut-off to 16, depending on learning from the pilot. In order to evaluate the pilot, we will be collecting feedback both from GPs and patients. The pilot will launch in 2025/26 Q1.

Youth support, genomics, clinical trials & biobanking

- Our **Youth Support Worker** continues to support TYA across the North Thames region, based at UCLH but with outreach to the designated hospitals. He has supported **over 100 young people** being cared for outside of UCLH in the last two years, and is in the process of writing up an evaluation of his impact.
- Our **genomics, clinical trials & biobanking coordinator** made huge progress on work related to the service specifications during her time with the team - unfortunately due to uncertain funding she left in September 2024 and has not been replaced. She helped with pathway mapping and education, improving access to whole genome sequencing, sample collection and banking, and clinical trials. The aims from the service specifications that we continue to work towards are:
 - **Clinical trials** – 50% of eligible TYA offered enrolment in clinical trials
 - **Tumour banking** – 100% of TYA offered access to tumour banking
 - **Genomics** – 100% of TYA offered access to diagnostic genomics where relevant

Funding pitches

There are a number of projects we are seeking funding for, and this year we began pitching to ICBs/Cancer Alliances to try to raise awareness of the need for TYA work and work with them on future projects:

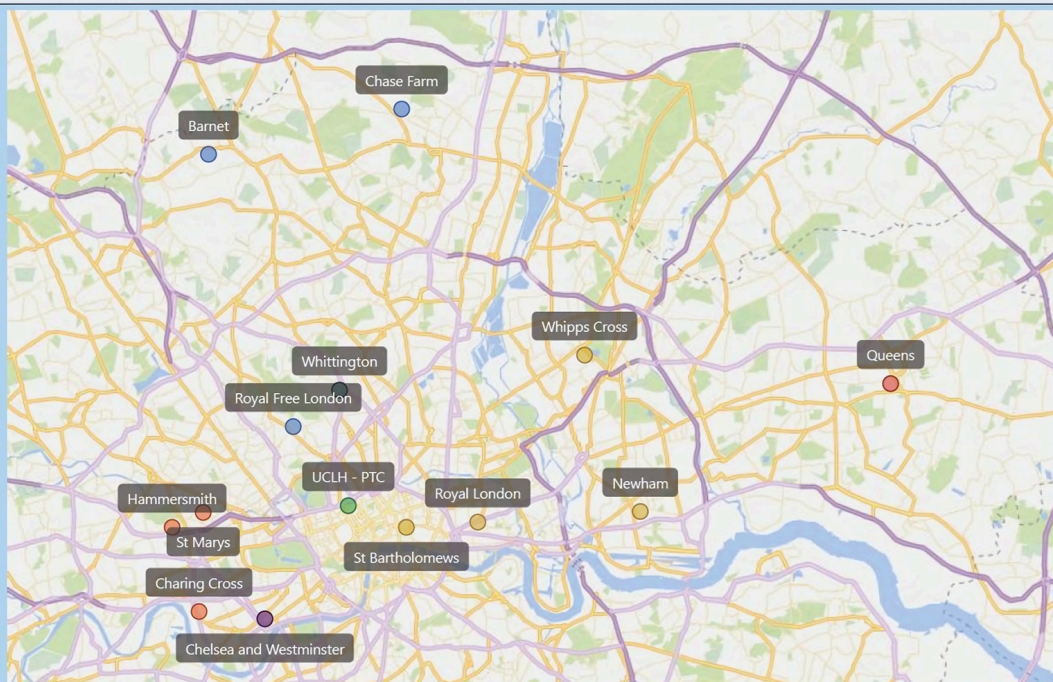
- **TYA CNS universal coverage** - integral to offering support to young people and to clinical teams, but also in leading the TYA agenda on issues such as delayed diagnosis, transition and joint care set up. Current disparity with CNS support, with only a handful of sites having access to a TYA CNS.
- **Psychology & youth work** - we developed a cost effective model for the region involving central, east and west hubs with one psychologist and one youth worker at each
- **MDT coordinator** - the decentralisation of TYA cancer care means that patients are not always flagged to the PTC and that the PTC does not have full oversight. TYA patients may be seen in very 'adult' based environments that may not be appropriate. An MDT coordinator would help to facilitate TYA MDT referral.
- **Genomics coordinator** - in contrast to paediatric patients, WGS for TYA patients undergoing a diagnostic biopsy outside of the PTC is very unlikely to be an option. Forging better genomic diagnostic pathways and education of referring teams across the network is crucial for them to be implemented.
- **Clinical trials and biobanking** - a Network Research Lead would ensure connection of services closer together, raise awareness of when a young person would be eligible for a clinical trial, and facilitate easy access and referral to the respective centres.

North Thames TYA Cancer Network Maps

North London Trusts

NTPN London Trust

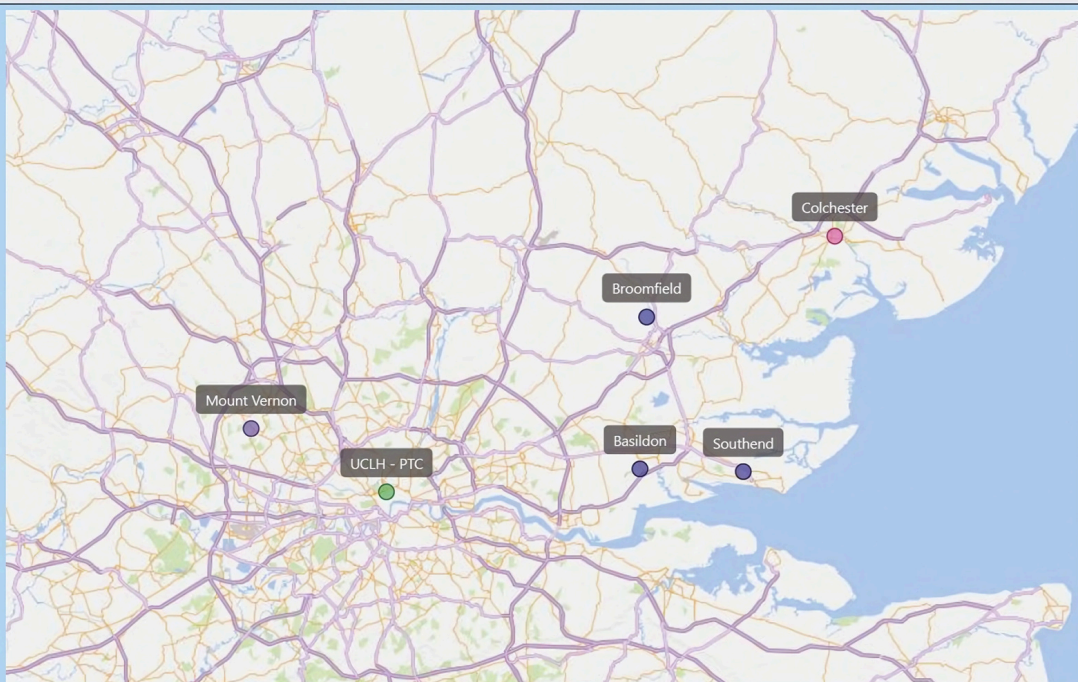
- Barking, Havering and Redbridge University Hospitals Trust
- Barts Health NHS Trust
- Chelsea & Westminster Hospitals NHS Foundation Trust
- Imperial College Healthcare NHS Trust
- Royal Free London NHS Foundation Trust
- University College London NHS Foundation Trust – PTC
- Whittington Health NHS Trust



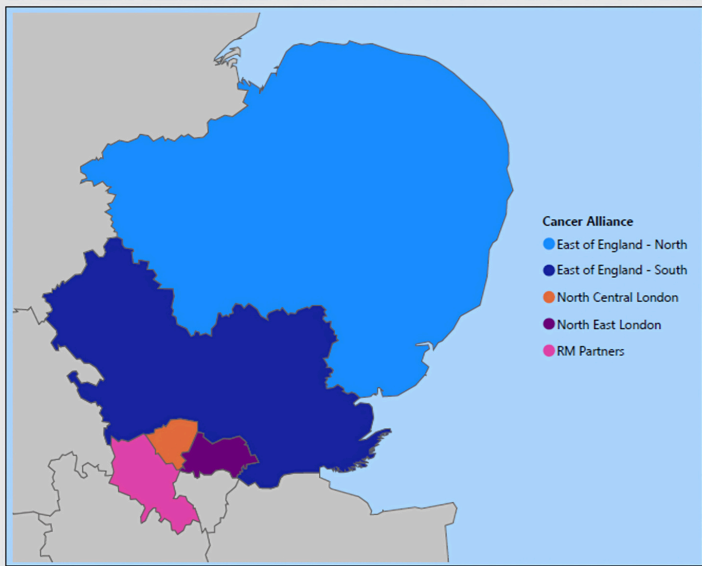
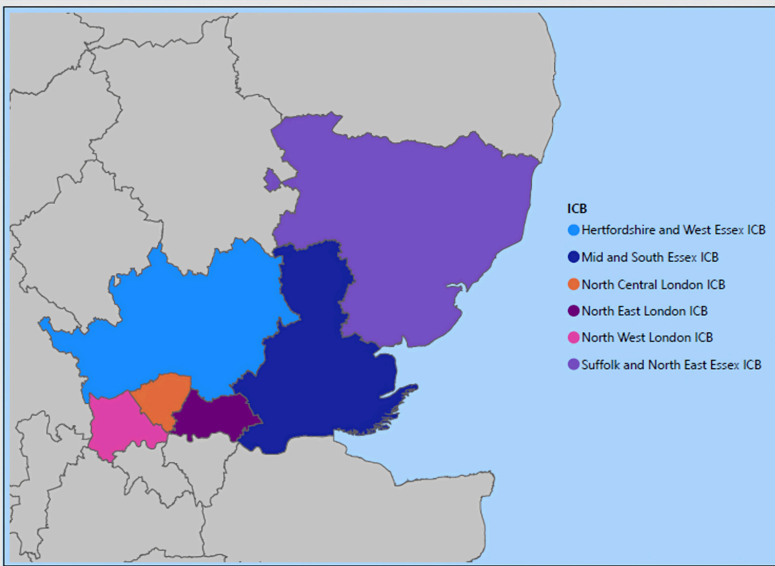
East of England Trusts

EoE Trust

- East and North Herts Trust
- East Suffolk and North Essex NHS Foundation Trust
- Mid and South Essex NHS Foundation Trust
- University College London NHS Foundation Trust – PTC



Our ICBs and Cancer Alliances





Dr Victoria Jowett
Clinical Director
Consultant Fetal Cardiolgist
Great Ormond Street Hospital
for Children



Adrienne Cottam
Lead Nurse and Digital
Innovation Lead



Gillian Riley
ECHO
Physiology
Lead



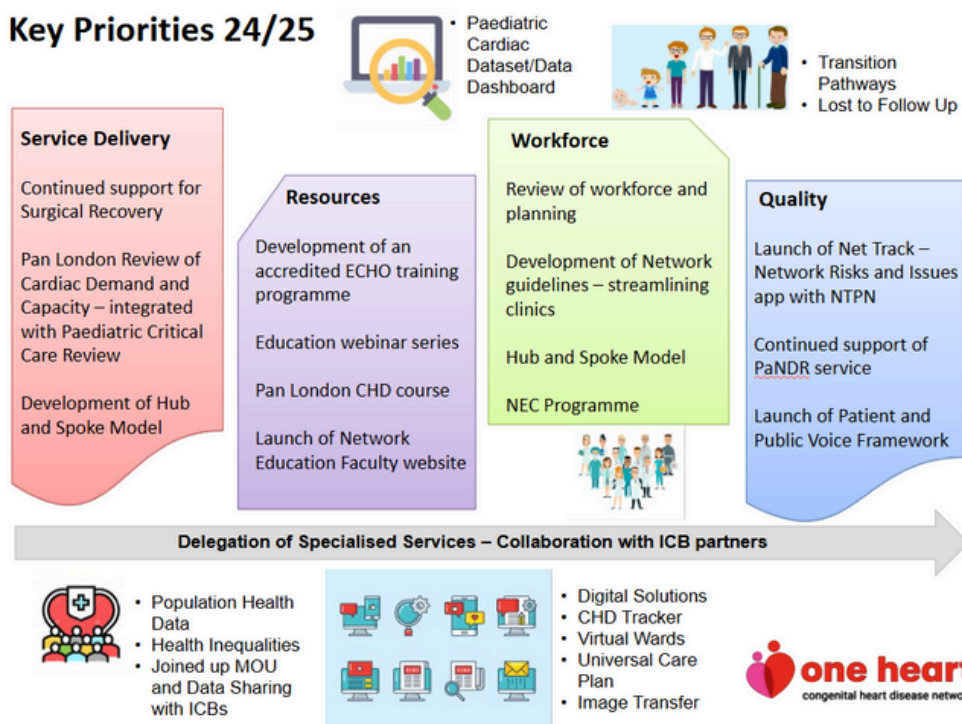
Dr Wilf Kelsall
Network Chair

In 2016 NHS England published national congenital heart disease standards and specifications for both paediatric and adult congenital heart disease. These standards are used as the basis for workplan development for the national and regional congenital heart disease networks.

Our Network Vision

- Put patients and their families/carers at the heart of everything we do.
- Remove variation in service provision across the Network hospitals to provide consistent quality of care.
- Embrace innovation to improve the quality of care outcomes.
- Collaborate on a system-wide basis across the CHD lifetime pathway

Key Priorities 24/25



THOUGHTS FROM THE ONE HEART CARDIC CONGENITAL HEART DISEASE NETWORK CLINICAL DIRECTOR

It is my pleasure to have the opportunity to highlight the work that we have been doing over the past year in the One Heart Congenital Heart Disease Network.

I was appointed as Clinical Director in June 2024. As a fetal cardiologist, central to my role is talking to parents about what to expect, and the anticipated journey, in the coming years for their child with CHD. I was therefore very excited by the opportunity to work in the network team who are focused on supporting and improving the entirety of the patient pathway from a pregnant mother, expecting a child with a congenital heart defect, through childhood, cardiac surgery and intervention and outpatient support into adult life. At the heart of this and core to its success is the collaborative relationship between professionals in the cardiac network and our patients and families.

There are many threads that make a successful and effective network and as a team we have sought to make progress this year across a number of areas:

- Our Network Lead Nurse, Adrienne Cottam leads the educational programme and we have continued to provide impactful educational events this year including cardiac foundation study days and a think cardiac educational event to support recognition of CHD in newborns. Many of you will have also worked with Gill Riley our Echo Lead for the Network who has been out and about providing hands on echo training across the network in addition to regular network webinars. Please have a look at our website where her teaching is now available!

We completed a feedback survey on our home monitoring service and a new pathway. This will be supported by new clinical guidelines for common conditions over the coming months.

We have ongoing commitment to innovation and are moving forward with digital innovation for referrals from the network, improving quality and safety monitoring and virtual ward.



Dr Victoria Jowett
Network Clinical Director
Consultant Fetal Cardiologist
Great Ormond Street Hospital for
Children



Service Delivery

Support with Surgical Recovery

- Level 1 Paediatric Unit (GOS) substantial backlog of P2 Cardiac Surgery post Covid.
- Ongoing work to support Network discussions re mutual aid.
- Network support of internal discussions at GOS re prioritisation and possible mutual aid with Independent Sector.
- Network support of external discussion with GOS and regional partners (Evelina/Brompton).
- Network support of external discussion and development of mutual aid plan with Leicester
- Submission and monitoring of backlogs at National Level as part of National ODN meetings

Demand and Capacity Review

- Supported with regional discussions re capacity at Level 1-unit Great Ormond Street.
- Decision to open 4 cardiac HDU beds 4 beds will support reduction waiting list by 2025 and will enable optimum waiting list of 80 patients to be maintained
- Additional capacity to be brought online achieved through building temporary capacity for cardiac children on existing ward and neonatal unit. Medium term work to establish dedicated bay will ensure resilience for future and utilisation of workforce in dedicated area
- Further discussions to determine profile of investment within contract for 24/25 and to adjust SDF funding received automatically via national team.

Workforce Innovation

ACHD/GUCH

- **Band 6 development posts** within team due to challenges in recruiting band 7 posts
- **Development of nurse-led clinics and advanced skills acquisition** to help with career pathways/retention.
- **Rotation** for nurses through sub-speciality areas.

Paediatric CHD

- **Network funded newly created Transition supportive band 4 role.** Transition Coordinator works with CNS team to enhance transition
- **2024 In development - Network Enhanced Practice nurse programme** in collaboration with Middlesex university /GOSH Learning Academy to recruit and develop Enhanced Practice nurse programme for Network nurses in level three Trusts.2024 pilot
- **NEC programme- (Nurse with Expertise in Cardiology)** Extension to the 'link nurse' role. Self-selecting senior nurses/educators become network Trust 'ambassadors' for the free education programme , disseminating education and participating in ALL Network and all in- house free zoom education from GOSH/Barts. Pilot 2021 -2022 , extended to 2023 -2025

EDUCATION AND NETWORK ROLE ENHANCEMENT

ACHD GOSH /BARTS 2024-2025 new free cross site ZOOM rolling programme of free ACHD education offered to network clinicians. Co designed with network educators.

- **ROLLING REMOTE EDUCATION PROGRAMME FREE** network CHD zoom education. Programme of co designed zoom education focused on network clinicians learning needs. 35 x zoom network study days 2021-2024 . 210 hours free teaching , more than 2200 attendees

Workforce

Workforce Review Programmes

- Submitting to national CHD workforce review surveys.
- Piloting new workforce roles e.g. joint transition co-ordinator between Level 1 paediatric and adult sites, Network physiologist/ECHO training post and NEC (Nurse with Expertise in Cardiology).
- Links with regional workforce review programmes NHSE London Region.
- GOS Programme to recruit nurses – focusing on domestic recruitment due to challenges with international recruitment.
- Partnership between Level 1 paediatric and adult site to look at new joint posts e.g. physiologists trained in paediatric and adults.
- Potential for joint posts PEC/Cardiologist Level 1 unit.

Developing Hub & Spoke Model

- Developing Level 3 'hubs' who will be formative link hospitals to Level 3 'spokes'.
- Potential for centralising outreach and minimising time Level 1 cardiologists spend at Level 3 units.
- Maximising training and education delivery e.g. ECHO training and better access to echocardiography in district general hospitals.
- Prevent unwarranted admissions or re-admissions – benefits to flow across the pathway/sector.
- Aligning of hub & spoke model with other paediatric specialties e.g. respiratory, oncology etc.
- Aligning of hub & spoke model with adult outreach clinics – improving the transition pathway

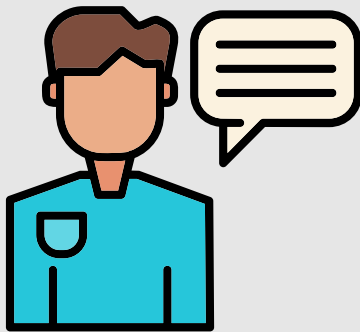
Risk & Governance Framework

- Development of a risk & governance framework
- Creation of Network risk & issues tracker 'Net Track' which is a digital solution, linked to the Network Digital Sit Rep Dashboard
- Network development of risk register to evolve to M&M meetings to discuss network cases
- Network support with pathway challenges especially cross network e.g. TVW/North London EoE/North London
- Network support with highly specialised commissioned pathways e.g. Heart Failure/Heart Transplant.
- Working with ICB partners to review new Patient Safety Agenda roll out and shared risks/issues across Network area.



PEC Feedback

The Network paediatricians with an expertise in cardiology are a vital feedback source for the Network in determining objectives and priorities. The Network Chair, Dr Wilf Kelsall, undertook a feedback study to better inform the direction of the Network and gaps that need addressing. In the future this will lead to the creation of an Outreach Working Group through 2025/26



Feedback was received from 13 out of 15 units surveyed. The objective was to determine what works well, what doesn't and to explore the possibility of potential hub and spoke models in future to counteract workforce and resource challenges

Challenges faced by the hospitals included the ability to undertake ECHO imaging, transfer of images, and secretarial support to the clinics

Outreach clinics are hugely beneficial to patients providing expert care closer to home and supporting the local paediatric teams

Parents have commented that clinics are crowded and rushed. They would like more time with the visiting clinician. It would save time if diagnostics could be done there at same time to stop the need to go to the Level 1 centre in addition

One size doesn't fit all - perhaps clustering clinics in future would allow for better use of money and resource and a better environment for staff and patients



Network Education

In meeting the needs of our Network stakeholders, the Network, led by Adrienne Cottam Lead Nurse, is committed to delivering a co-developed programme of education, meticulously and collaboratively adapted to the specific needs of Network clinicians from all care areas, including ward, community and acute care - to ensure that nurses, AHPs and junior doctors are equipped with the skills and knowledge they need to practise.



The Network wants to ensure pitch and content are meeting the learning needs of Network clinicians so that they feel confident to deliver safe and effective care to congenital heart disease patients throughout their lifetime of their care. The Network actively recruits or partners with expert senior network educators. The team encourage input, solicit feedback and reassess in order to develop Network teaching that is suitable. Building on previous sessions to enhance understanding. The first Network NICU and fetal study days were developed this way.

National profile



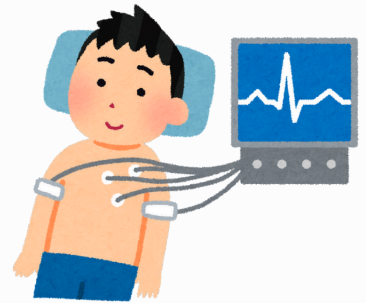
Our OneHeart team are this year hosting the annual UK national Cardiology Conference (BCCA), with a nursing focus on digital leadership as a new frontier for clinicians working throughout the health service. We'll be presenting our current digital innovation projects, with practical advice for those wishing to move into this exciting sphere of patient care and service improvement.



Network ECHO Training Programme

Access to local physiology ECHO services continues to be a challenge for the Network's local hospitals. In order to try to provide this essential service closer to home, the Network has continued to fund a Network ECHO physiologist who delivers a full training programme including outreach sessions at local hospitals:

- All based around EACVI syllabus
- Monthly newsletter with articles, education opportunities
- Developed website – access to protocols and case studies
- Webinars – e.g. single lesion or function assessment
- Agreed recertification with Royal College Paediatrics
- Study days using the echo simulators
- Support through exam and logbook
- Direct Observation Practical Skills Assessment (DOPS)
- Visits to the Level 1 paediatric centre, Great Ormond Street



**SCAN QR CODE
FOR MORE INFO**



Gillian Riley
ECHO
Physiology
Lead

Transition Pathways



The Network has continued to support with the review of potential improvements to the CHD transition pathway between Great Ormond Street Hospital and St Barts Hospital. The successful outcome of the Network funded CHD transition coordinator pilot has been shared with both of the Trust teams, who are looking to see how they can substantiate the post. The post has improved the experience of young people on the transition pathway, reduced lost to follow up and allowed better monitoring of the transfer of care.

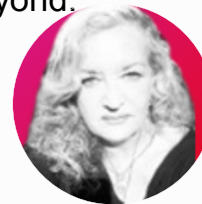


Digital Innovation Programmes Mission Statement

In developing digital programmes for the One Heart CHD ODN and for the wider NTPN, the Network's strategy mirrors that of the National Health Service, aiming to overcome the flaws of analogue paper systems, unify electronic patient records, address inequities in access to specialist services and reduce administrative burden on clinicians.

The final tenet is a softer goal, and even more important with our children and young people – to engage patients and families with their own care and reduce the challenge of loss to follow up, which is still a prevalent issue for transitioning young people as they make the often wrenching move to adult services.

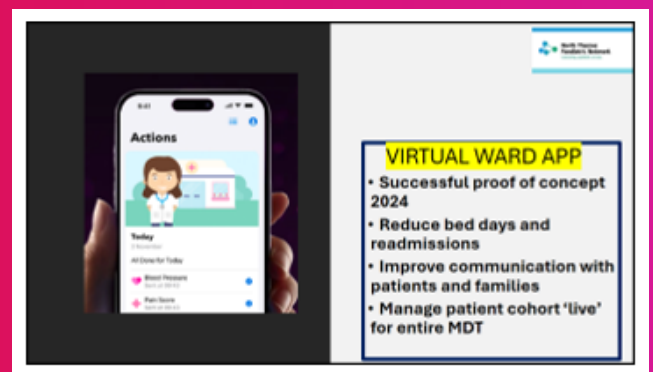
I delivered an update recently at the stakeholder day and reiterate my desire to hear from you if any of the current projects (below) resonate with you. I'll be delighted to support and build your project collaboratively, identify your key stakeholders, help to locate funding and take you from development to implementation and beyond.



Adrienne Cottam
Lead Nurse and
Digital Innovation
Lead

Virtual Ward Pilot 2024-2026

- In 2024 the Network supported the proof of concept project in using a digital 'Virtual Ward' adjunct (patient app) to enhance home monitoring for cardiac infants.
- Goals – to reduce hospital bed days and hospital appointments, reduce disruption for families and provide an app to monitor and manage symptoms, enhance communication with families and reduce anxiety. 'Care close to home'.
- Uses a live dashboard to support management of entire cohort for MDT
- The Network developed and implemented the platform (app) with the Netherlands vendor who agreed a cost-free partnership with the team
- Now expanding to explore a national cohort of patients with inherited cardiac disease (ICVD), with a focus on young people and teenagers, empowering them to manage their own care, support symptom management, reduce clinic visits and family disruption and to recognise when escalation of care is required.
- The Network is exploring the possibility of tech enhanced home monitoring, and the possibility of the 'holy grail' – 12 lead ECGs at home.



A New National Online Referral for Paediatric Heart Transplant UK

The Network is particularly pleased to have progressed with unifying and digitising the paediatric national heart transplant services (GOSH and Freeman Newcastle) this year, customising an online communication, advice and referral platform, joining up patient information flow nationally and digitising this time sensitive referral process.



Following our Digital Innovation Lead's (Adrienne Cottam) successful development of a national digital referral, advice and communication tool for adult respiratory ECMO services (2020 Covid response redeployment) the Network explored similarly time sensitive clinical services in paediatrics. It was not difficult to enlist the innovative decision makers and clinical leads in aiming to unify and digitise paediatric heart transplantation, bringing equity of access to this specialist service nationally and reducing the risks of the inefficient, flawed and inconsistently documented paper referrals and ad hoc calls.

The Network have chosen this same platform, referapatient from Bloomsbury Health-

- they are a trusted NHS supplier used in over 80 Trusts for similarly time sensitive referrals
- referrals are supported by AI enhanced transcription which becomes part of the patient record, reducing admin burden for the referring medic
- a particularly useful function is the ability to 'port' in seconds, a full referral with imaging to another specialist team if bed challenges mean the patient should be seen in a different centre.
- data storage and management are reliably robust, based in the UK and with a 99.9% platform uptime. Patient data is stored on Amazon Web Servers (AWS), a secure UK-based cloud environment and all data remains the property of the two NHS Trusts and is handled according to GDPR and NHS IG policies
- importantly, human to human contact is not lost, expert advice is still readily available and encouraged during and after referral
- the Network looks forward to reporting back on this venture in the 2025/26 annual report when there is some audit data.



Little Journey 2024-2025

- A free to patients and family's app in use already to support reduction in anxiety, and provide real, live tours of hospitals and procedure rooms, with animated characters engaging children aged 4-8 and 8 – 12years
- The Network recognised how effective this could be in supporting young people (12- 21 years) as they make the often wrenching move to adult services and negotiated a partnership with the vendor to develop a transition module for 12- 21 year-olds
- Key goals – to co design the new module together with young people to build a supportive tool to engage and educate and importantly, to reduce loss to follow up which is a recognised national and international concern for transition age young people as they move to adult services
- Plan – to pilot co design for (pan London population) cardiac children and young people, before offering to wider NTPN clinical services



Tendable

A digital tool the OneHeart team developed with the Tendable vendor to simplify hospitals and clinical services in self-assessment against national CHD standards. At the request of Commissioners who saw the potential, we are now re developing for a National UK wide peer review pilot for cardiac service in 2025/2026, before exploring utilising the platform for other clinical services peer reviews.

Peer reviews are currently completed by large teams travelling to peer review other centres over days. The goal of this clinician friendly app is to reduce resource waste, standardise review processes in measuring against national standards and provide vital data for future service enhancement for the commissioning teams.



North Thames Paediatric Epilepsy Network



Dr Amit Bali
Epilepsy Clinical Lead
Consultant Paediatrician
Royal London Hospital



Denise Edwards
Epilepsy Nurse Lead



Lee Butler
Epilepsy Specialist Nurse
(Epilepsy pilot)



Dr Laurence Hasson
Clinical Psychologist

Key Achievements 2024/25

Among the main achievements for this financial year were:

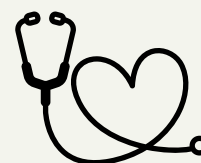
- The launch of the Network Mental Health Screening pilot (due to end December 2025) and Nursing pilot (which ended in March 2025). The Network has achieved significant progress through this work, which is summarised in more detail below.
- The Network's audit of Sudden Unexpected Death in Epilepsy discussions was presented as a poster at the 2025 RCPCH conference.
- The Network had approval this year to develop epilepsy-specific Universal Care Plan (UCP) fields, which it aims to achieve in 2025/26.

Thank you to Lee and Denise for being part of the nursing pilot!

Addressing variation in care between epilepsy services

The Network has:

- identified services where access to an epilepsy specialist nurse (ESN) is an issue (data via epilepsy12, surveys and site visits)
- identified pathway/access issues to investigations such as MRI and EEG (data via epilepsy12 and surveys)
- facilitated sharing of good practice regarding MRI under sedation
- undertaken pilot ESN-led clinics in both NCL and NEL (Royal Free, Barking & Dagenham), with a particular focus on young people with Learning Disabilities (LD) and autism. This aligns with NHS England's commitment around health inequalities in paediatric epilepsy care ([CORE20PLUS5](#)).
- identified variation in care planning, including issues in sharing effectively with families and schools/colleges
- identified variation in the dissemination of information around SUDEP with CYP/families (through specific audit). The Network presented its results from the initial audit of the baseline position pre-implementation of the SUDEP checklist as a poster at RCPCH and the Network's work was also featured on SUDEP Action's website. The Network now plans to do a follow-up survey to review. The SUDEP poster can be seen on the following page.





UNDERSTANDING PRACTICE AND CONFIDENCE IN DISCUSSING SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP) IN CHILDREN ACROSS THE NORTH THAMES PAEDIATRIC NETWORK

Authors:

Lee Butler, Denise Edwards,
Dr Amit Bali, Lauren Martin



North Thames
Paediatric Network
Connecting paediatric services



North Thames
Epilepsy Network

INTRODUCTION



Sudden Unexpected Death in Epilepsy (SUDEP) is a significant cause of death in children and young people (CYP) with the condition, **affecting 1.2 per 1000 per year** – similar to adult figures (1). For this reason, the NHS England national bundle of care for children and young people (CYP) with epilepsy (2) states **all CYP should receive appropriate and tailored information on risks of SUDEP**, and ensuring this is **reviewed annually and documented**. The charity SUDEP Action (3) has been developing a **paediatric-specific tool** to augment these discussions; however, little is known about the **baseline practice of clinical staff**. We sought to **gather data** across the North Thames Paediatric Network (NTPN) from epilepsy care professionals.

OBJECTIVES



- To audit **current SUDEP discussion practices** in the North Thames region
- To encourage **adoption of a structured approach** such as the SUDEP Action checklist

METHODOLOGY



- Questions were developed by team members, and reviewed by wider stakeholders, after which a **survey was created** on Google Forms.
- This was **shared with all epilepsy professionals** across the NTPN via email and WhatsApp, running over a two-month period (July and August 2024).

KEY FINDINGS



20 responses were received from professionals across the NTPN, involving Epilepsy Specialist Nurses, Advanced Clinical Practitioners, and Consultants, representing 12 services in total. **17 respondents (85%) did not use a protocol** to help in structuring their SUDEP discussions (Figure 1). Regarding **confidence levels**, **14 respondents (70%)** replied they were 'not confident' or 'somewhat confident' in having SUDEP discussions (Figure 2). There was wide variability in the numbers of CYP (within each professional's clinical caseload) that professionals felt were appropriate for a SUDEP discussion. Respondents commented that it can be **difficult to know how to start the conversation** and they are worried about **increasing anxiety or overwhelming parents with information**, especially given SUDEP is rare. Inappropriate **clinic settings** and having **insufficient time** in clinic appointments were also raised as barriers. Respondents felt SUDEP discussions should be **clearly documented** and families **signposted to resources**.

Figure 1: Participant responses when asked 'Do you have a protocol for discussing SUDEP with patients?'



Figure 2: Participant responses when asked 'How confident do you feel discussing SUDEP with patients?'



CONCLUSIONS

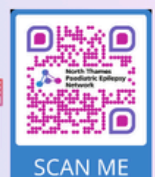


The results show there is **wide variation in confidence and practice around SUDEP discussions across the NTPN**. There is little in the way of standardisation (e.g. frequency of discussion), coupled with limited confidence, which contributes to inequity in access to information. SUDEP Action's paediatric checklist represents an **opportunity to drive improvement**. We are currently encouraging implementation of this tool and plan to **re-evaluate changes in practice** across the NTPN.

REFERENCES



- Sudden unexpected death in epilepsy in children, Developmental Medicine & Children Neurology 65 (9), 2023
- National bundle of care for children and young people with epilepsy, National Health Service England (NHSE), 2023
- Children's SUDEP and Seizure Safety Checklist, SUDEP Action, 2024



Improving referrals into tertiary services and the Children's Epilepsy Surgery Service (CESS)



The Network has:

- mapped secondary-tertiary services, pathways and models of care across the region.
- achieved consensus on the principles of shared care.
- designed a 'shared care checklist' for services to be able to self-rate against.

Supporting the mental health and wellbeing of CYP with epilepsy



The Network has:

- identified services with defined mental health and neurodevelopmental pathways, and also those with pathway issues (epilepsy12, surveys and site visits)
- launched our epilepsy mental health pilot (on subsequent page)

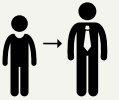
Additional Work



The Network has:

- Worked with our ICBs and NHSE London's BCYP team to respond to the Sodium Valproate/Topiramate MHRA alerts, identifying an exemplar model, and advocating for equivalent, appropriately resourced models across the region.
- Partnered with NHSE London's BCYP team and the South Thames Paediatric Network, to update the previous 'Epilepsy in Schools' guidance (Healthy London Partnership).
- Collaborated with Tiny Medical Apps and Young Epilepsy to develop an app that will help CYP and families with self-management, education/awareness, peer support
- Met with LAS and other stakeholders to articulate concerns about the use of IM midazolam in the pre-hospital setting.
- Sat on the clinical group contributing to a health economic analysis commissioned by NHSE, assessing the impact of the specialist workforce on the care of CYP with epilepsy (awaiting publication).

Improving the transition from paediatric to adult epilepsy services



The Network has:

- mapped how services offer transition or, when unable to do so formally, how they transfer care to adult services (epilepsy12, survey, site visits)
- investigated pathway issues and offered our support to resolve them
- collaborated with YELL (Young Epilepsy Loud in London) to ensure the voice of CYP is at the centre of our work
- identified different transition models that are in use.

Network Epilepsy Webpage



Epilepsy Universal Care Plan (UCP)

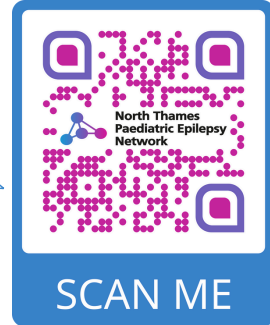
- Following on from the development of the generic 'babies, children and young people' fields for the Universal Care Plan (UCP), the Network felt it would be helpful to have epilepsy-specific fields (that could be used by both children and adults) built into the UCP, to be used as an innovative digital care plan across London. The UCP is accessible by anyone with an NHS email address, including school nurses, is integrated with existing patient record systems, and is linked to the NHS app for patient use, replacing paper versions.
- The Network established a working group to help design the fields, and received approval to progress development at the beginning of 2025. The Network is now in the process of building a prototype to be approved by stakeholders and hopefully released by the end of 2025.

Piloting mental health screening in epilepsy clinics (funded by NHS England CYP Transformation team)

Background

Developed in 2016 by NHS Lothian, PAVES (Psychology Adding Value: Epilepsy Screening) is a mental health screening and support program for children and young people with epilepsy. The PAVES program has been able to identify a significant level of psychosocial difficulties, otherwise missed in this vulnerable population, and meet some of the psychological needs using a stepped care intervention model. PAVES focuses on developing strong links with third sector and community organisations. From 2017-2019, evidence showed that the PAVES model was highly effective in significantly reducing CAMHS referrals, and saving the NHS a significant amount of money for every CAMHS referral avoided. As part of the National Epilepsy Bundle of Care, NHS England is therefore piloting the PAVES model nationally.

Epilepsy
Mental Health
webpage



CYP with epilepsy are up to 4 times more likely to develop a mental health problem than their peers, but are not routinely screened in their epilepsy clinics despite Epilepsy Bundle of Care guidance

- In North London, our pilot has been running in epilepsy clinics at Royal London Hospital and Whipps Cross Hospital (Barts Health NHS Trust) since September 2024.
- NHS England have developed an online screening platform which contains two digital questionnaires for families to complete before attending their appointment. These questionnaires are the SDQ and the 'Epilepsy and Me' questionnaire. They can be accessed either by a link or a QR code, and take 5-10 minutes to complete. Young people (aged 5 and over) with epilepsy complete the screening measures, and the results are automatically scored up and a report emailed to clinicians. The results are viewed by clinicians including a clinical psychologist, to help identify unmet mental health needs and consider what intervention(s) would be appropriate.
- Various interventions can be offered to CYP and their families to help support their mental health, including signposting to local support, Parent Workshops, a Psychosocial Intervention Group for Adolescents with Epilepsy (PIE-r Group), and 1:1 therapy using the Mental Health Intervention for Children with Epilepsy (MICE) approach. The Network has created a website to signpost people to relevant local resources: <https://ntpn.co.uk/epilepsy-and-mental-health/> as well as a Padlet, which can be accessed via this QR code:



- As of the end of March 2025, around 80 patients had completed the online mental health screening. The Network's response rate is approximately 30% of those invited to complete the screening. The results break down as approximately 39% 'Green' (no significant unmet mental health problems), 22% 'Amber' (some unmet mental health needs), and 39% 'Red' (significant unmet mental health problems).
- The next phase of the project, which started in January 2025, is shifting focus onto interventions, and the Network is currently in the process of setting up and running more interventions. Three patients have completed individual therapy so far (approx. 10 x 1:1 weekly sessions) with four more cases ongoing or about to start very soon. Fourteen parents have attended parent workshops so far, with more planned for the near future. A PIE-r intervention group for five adolescents was run by a clinical psychologist and an epilepsy specialist nurse (ESN) for 6 sessions, and a waiting list is ongoing for the next group.

Epilepsy nursing pilot (funded by NHS England CYP Transformation team)

In Spring 2024, two nurses were hired to run a 12-month nursing pilot in the North Thames region, in line with the NHS England Children & Young People Transformation programme objectives. The pilot ended on 31st March 2025. The initiative aimed to address care inequalities and gaps highlighted in the National Epilepsy Bundle of Care and the Core20PLUS5 priorities for children and young people (CYP) with epilepsy.

Key challenges:

- Significant variation in epilepsy service provision across the network.
- Limited access to Epilepsy Specialist Nurses (ESNs), especially in high-need populations.
- Challenges in mental health support, SUDEP information provision, and transition planning.

Pilot clinics:

The pilot clinics were a central feature of this programme, designed to provide targeted, equitable access to epilepsy care for under-served groups, particularly CYP with learning disabilities and/or autism. Each clinic aimed to deliver holistic, personalised, nurse-led care, addressing both medical and social needs. The design of the clinics was informed by an initial gap analysis (involving data review and site visits), ensuring that the chosen locations represented areas of greatest need. Multidisciplinary collaboration with local services was crucial in shaping and supporting clinic delivery.

• Clinic Locations:

- NCL: Royal Free Hospital (Kentish Town Health Centre)
- NEL: North East London Foundation Trust

• Patients seen:

- In total, 28 patients were supported by the nurses in these clinics

Case study: Complex epilepsy with learning disability & autism

- **Medical History:** Lennox-Gastaut syndrome, VNS implant in situ, moderate-to-severe learning disability and autism. Genetic mutation present increasing the risk of Brugada syndrome.
- **Challenges Identified:** The young person's mother was unclear on how to manage emergency situations involving seizures, particularly when hospitalisation was needed. There was also concern regarding the legal responsibilities as the young person approached adulthood.
- **Actions Taken:** Conducted an in-depth consultation focused on transition education, highlighting the key stages and what to expect, provided guidance on best interest decisions and discussed the Mental Capacity Act and Deputyship for health and welfare, developed a bespoke care plan outlining:
 - Out-of-hospital emergency response steps.
 - In-hospital management including medication to avoid due to Brugada risk.
 - Procedures for MRI/surgery with a VNS in place.
 - Contact details for emergencies and points of escalation.
- **Outcome:** The mother felt more empowered and confident navigating emergency care, transition, and legal processes. Feedback from both family and the Royal Free epilepsy service was extremely positive, recognising the care plan as a valuable document for ensuring consistent emergency care.

Other work:

The nurses were involved in a number of other projects described on previous pages.

Conclusions:

The pilot confirmed:

- The epilepsy bundle of care is not fully embedded in practice.
- Wide variation exists in ESN support, mental health services, and transition planning.
- Workforce shortages and inconsistent access hinder equitable care.
- SUDEP discussions are not routinely undertaken but improved through targeted interventions.

Recommendations:

- Sustained investment in the paediatric epilepsy nursing workforce.
- Enhanced data collection and service audit mechanisms.
- Expansion of standardised care tools, such as shared care and SUDEP checklists

PAEDIATRIC NEUROLOGY NETWORK



Dr Prab Prabhakar
Neurology Clinical Lead
Consultant Paediatric Neurologist
Great Ormond Street Hospital for Children



STROKE / 'BRAIN ATTACK' - 2024/25 Updates

- Continued work on development of a paediatric 'brain attack' pathway for the North Thames region** - the Network developed a pathway based on the RCPCH stroke guidelines, and a business case proposing a low-cost virtual MDT that would provide support to local hospitals across the region. This has been discussed in several forums, including with NHS England, and the Network is hoping to progress this in 2025/26.
- Morbidity & Mortality / risk meetings** - the Network has hosted a number of neurology M&M meetings in 2024/25, including the discussion of multiple cases of delayed diagnosis or pathway problems involving stroke in children. This links closely with pathway work and the Network has identified the primary issues to be the recognition of stroke, timely and appropriate imaging (CT and CT angiogram), and accurate interpretation of, and action on, the imaging results. The Network plans to establish a neuroradiology working group in 2025/26 to discuss some of the imaging-related barriers and possible solutions in more detail.
- 16-18 year old pathway with Queen Square** - the Network has continued discussions relating to the provision of GOSH support for the Hyper-Acute Stroke Unit at the National Hospital for Neurology & Neurosurgery at Queen Square. The Network has developed a potential plan for GOSH providing input into the care of the 16 and 17 year old patients being treated on the HASU, and is in the process of consulting with neurovascular colleagues at GOSH to review the level of input that could be provided and the best staff groups to provide this. As part of this, the Network hosted a visit with David Hargroves, National Stroke Director in Oct 2024.
- Educational visits to Whipps Cross and Southend** - the Network spoke at the London Emergency Medicine CYP (LEMCYP) meeting at Whipps Cross hospital in June 2024 on the issues involved in diagnosing brain attacks in children, and potential solutions. The Network also delivered education to the emergency teams at Southend in July 2024, which was an excellent session with very engaged resident doctors. The Network is aiming to expand its' educational programme in 2025/2026 and possibly develop videos and training resources for resident emergency doctor inductions, and provide training to nursing staff in emergency departments, who the Network have begun to contact to propose teaching sessions.



RCPCH 2017 stroke
guidelines

Extract from proposed 'brain attack' pathway



North Thames
Paediatric Network
Coordinating paediatric services



3. Proposed pathway

1. Patient presents or is transferred to local ED

- 2. Identification of 'brain attack' symptoms
 - FAST positive? (face weakness, arm weakness, speech problems)
 - Acute focal neurological deficit
 - Speech disturbance
 - Unexplained, persistent change in conscious level (GCS $\leq$ 12 OR AVPU $<$ V)

3. Commence emergency management

- Consider urgent intubation if GCS $\leq$ 8, AVPU $\leq$ P, if there is loss of airway reflexes or suspected/proven raised ICP
- Target EtCO₂ 4-5
- Consider mannitol/hypertonic saline
- Administer O₂ and target SpO₂ $\geq$ 92%
- If circulation is compromised deliver 30ml/kg intravenous isotonic fluid bolus (PlasmaLyte 148 or Hartmann's) if Sodium $\geq$ 135 OR 0.9% Saline if Sodium $\leq$ 134
- Perform capillary glucose test within 15 minutes of presentation. If $\leq$ 3 deliver 2ml/kg intravenous 10% dextrose and consider hypoglycaemia screen
- Dual IV access and bloods for venous/capillary blood gas (including lactate), FBC, PT, APTT, fibrinogen, U&E, Glucose, Group and Save, CRP, LFT.

4. Imaging undertaken locally within 1 hour

- Local team recognises urgency of 'brain attack', assesses and requests appropriate imaging (CT/CT angiogram)
- ED doctor to go down with patient for CT scan so CTA can also be done if stroke suspected
- Imaging reported by local neuroradiologist

NOTE: Also consider stroke in children with:

- New onset focal seizures
- New onset severe headache
- Ataxia
- Rash
- Resolved acute focal neurological deficit
- Sickle Cell Disease (if stroke and disease is suspected or present, discuss with Paediatric Haematologists. Thrombolysis is not indicated in sickle cell disease and these patients warrant urgent red cell exchange. Ongoing liaison with neurology is also important in managing these patients.)

For children with any of the following:

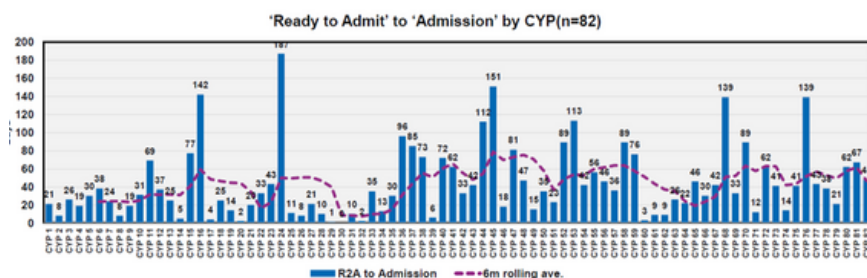
- GCS $\leq$ 8
- APTT $>$ 40
- Loss of airway reflexes
- Proven raised ICP or clinical evidence raised ICP
- This priority is urgently protecting the airway, and an anaesthetist should attend to intubate and ventilate. Control of raised ICP will be aided by tight control of end tidal CO₂, head $\leq$ 5.
- Hypertonic saline/ventral should be considered.
- Nurse with head at 30 degrees if possible.
- Liaise with Neurologist, Neurosurgeons and CATS for guidance on time critical transfer to the nearest neurosurgical centre
- Aggressive avoidance of hypoxia
- Maintain normal blood glucose
- Aim High Normal Sodium (140-145)

NEUROREHABILITATION - 2024/25 Updates

- Neuro-rehabilitation provision has been repeatedly flagged as an issue in the North Thames region. Demand currently outweighs capacity in the system and pathways for receiving neuro-rehab care are unclear and inconsistent. This results in:
 - Long waits in acute tertiary beds – delayed access to care
 - Impact on acute bed capacity and system flow
 - Unquantified impact on short-term and long-term outcomes for CYP and families
 - Poorer patient and family experience
 - Variation in applied rehabilitation for patients that are not yet fit for discharge from hospital
 - Increased health inequalities (acquired brain injury is linked to higher levels of social deprivation)
- The Network decided to add neurorehabilitation to the 2024/25 workplan, with support from South Thames and NHS England
- **Data gathering** - the primary focus in 2024/25 has been on data gathering and pathway mapping to understand where children with acquired brain injury are reviewed and treated, their waiting times and the gaps in current care provision. As part of this the Network met with The Children's Trust at Tadworth who provided data showing the numbers of patients referred and rejected, as well as waiting times.
- Working group - the Network arranged and chaired a working group meeting in February 2025 to discuss these issues on a wider level, including receiving a national update on the development of new service specifications to replace the current ones that were published in 2013.
- The Network has arranged meetings with various stakeholders for 2025/26 to continue scoping and then hopes to run a further working group meeting to present demand and capacity work to date

Case study from GOSH and example data from The Children's Trust at Tadworth

- Between Apr-19 and Mar-24, the average wait time from when a CYP is 'ready to admit' to admission to The Children's Trust for a CYP with a host London ICB/ CCG was **44.2 days**.



Case study – non-traumatic brain injury

- 14-year-old with stable type 1 diabetes mellitus
- Subsequently developed diabetic ketoacidosis and had a cardiac arrest with significant brain injury. Developed severe dystonia and movement disorder and needed specialist neurological input at GOSH to manage this.
- During this period, he was waiting for a suitable neuro-rehabilitation bed and was unable to be repatriated due to lack of neuro-rehabilitation provision in the district general hospital (DGH).
- Meanwhile, another child with presumed optic neuritis and new onset of demyelination could not be admitted due to lack of beds in the acute ward and this led to delay to initiation and management of this condition where early intervention with steroids and plasma exchange has the potential to save and preserve sight.

OTHER NEUROLOGY WORK - 2024/25 Updates

- **Motor Disorders** - The network are looking into how children with movement disorders and tonal issues are managed across the network. This piece of work is supported by community paediatricians who often treat very complex children. The Network will work with colleagues to design a survey to gain a better understanding of the existing expertise within the region, the patient flow and importantly how things can be improved. Once the survey has been analysed the Network will meet with the group to agree on priorities and how best to improve support and link specialist services with the region.

EMERGENCY PATHWAYS



Dr Giles Armstrong
Clinical Lead

Consultant Paediatric Emergency Consultant
Royal London Hospital

Future Plans 2025/26

The Network has plans to resource and support some emergency pathway projects through 2025-26. This will be in conjunction with ICBs.

- Support ICBs with reviews of paediatric emergency departments. Standardised guidelines and information posters throughout paediatric emergency departments. To date reviews of all paediatric emergency departments in North East London have taken place.
- There has been anecdotal information shared by the LEMCYP group on an increase of children and young people (CYP) who are attending the Emergency Department (ED) in crisis and behavioural distress who require community placement in order for the CYP to be in a safe environment. Throughout 2024-2025 the network will be collecting data on this cohort of patients for both North and South London.
- Representation and collaboration with London Emergency Medicine Special Interest Paediatrics Group
- Informing the Networks development together with One London and NHS Digital of Universal Care Plan section for CYP.

Adolescent Resources

- The team worked alongside Louisa Dudin who is the Lead Nurse for Children and Young Peoples Project at Queen Square to create a webpage of resources for adolescence to access, topics include education, finances, mental and sexual health, internet safety, mentoring and more.
- QR code was then generated and placed on a business card so it is easy for clinicians to hand out to their adolescent patients in clinics.
- This page is our 5th most accessed page to date.



EMERGENCY PATHWAYS



Dr Giles Armstrong
Clinical Lead

Consultant Paediatric Emergency Consultant
Royal London Hospital



**North Thames
Paediatric Network**

Connecting paediatric services

Education Webinar

Small Changes, Big Impact



**National
Autistic
Society**

'Autism Inclusion in
Emergency Medicine Departments'

31st January 12:00 – 13:00

Agenda:

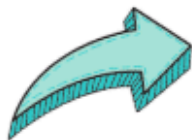
Following on from a London wide learning event for the Urgent and Emergency Care pathway for Babies, Children and Young People. We would like to invite you to a focused webinar sharing the experience of and learning from Barts Health Emergency Department's journey to accreditation from the National Autistic Society (NAS).

The session will cover a range of approaches from quick wins with limited resources through to the full process of NAS accreditation all with a focus on the impact these changes can make to patients, carers & staff

By Hannelore Bout, Autism Accreditation Consultant, National Autistic Society
Giles Armstrong – Consultant in Paediatrics Emergency Medicine
Andrew Carpenter, Autism Lead, NHS England Regional LD&A team

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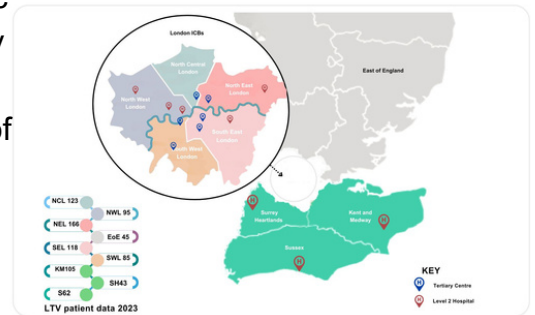
The Network collaborated with the **National Autistic Society** to create a webinar and resource for paediatric emergency departments to become more inclusive for autistic patients.

PAN THAMES PAEDIATRIC LTV PROGRAMME



The Pan Thames Paediatric LTV programme is jointly hosted by the North Thames Paediatric Network and the South Thames Paediatric Network. It's aim and funding is driving improvements in the delivery and quality of healthcare for babies, children and young people requiring Long Term Ventilation (LTV) and improving the efficiency of the use of resources across hospital and community settings.

The Programme covers both the NTPN, and South Thames Paediatric Network (South London, Kent and Medway, Surrey Heartlands, Sussex).



Highlights 2024/25 – [click here for the full report](#)

Education & Training

Expert specialist training was delivered across:

- 9 out of the 10 commissioned level 2 HDU
- 60% of all the 23 level 1 HDU, and 2/3 of the level 1 HDU who have previously admitted an LTV child
- Good adoption of the [LTV Clinical Guideline](#).

557
Staff
trained

80%
Increased
confidence

140
eLearning
users

100%
eLearning users
recommend it

Housing & welfare resources for staff

- **Housing enquiries** increased by 75%, reinforcing the ongoing need for accommodation and discharge-related support.
- **Immigration support** is an emerging area, with a 50% rise in enquiries, highlighting a growing need for specialist advice where status affects access to housing, financial assistance, legal support, and advocacy services.
- **Charitable & welfare support** the website analytics shows high engagement, indicating that online resources are meeting demand effectively.

NTPN e-learning platform

Pathways

Over the course of 2024/25 the programme has supported network colleagues with difficult patient pathways, through targeted education and training and/or facilitating discussions around difficult delayed discharges.

The Pan Thames Paediatric LTV Programme “have been instrumental in guiding this very complex discharge. Having the strategic support when liaising with multiple trusts has been not only been helpful but also a great learning experience for our team. The education support in the DGH has been instrumental in giving us more options for step downs and keeping the children under our care closer to home and their families.” LTV CNS, Tertiary LTV Centre

CLINICAL DIRECTOR'S CLOSING WORDS



When I applied to join the North Thames Paediatric Network as one of the Clinical Directors, I spoke of my view of the Network as the antidote to the uncertainty and challenges which underlie the delivery of equitable and accessible care for the children of the North Thames region.

In the last 9 months I have witnessed the team delivering across the workstreams demonstrating leadership and clarity supporting our network partners with education and collaborative guidance.



As the Integrated Care Boards of NCL, NEL, and NWL have taken on increased responsibility for delivery of specialised children's care and existing acute care pathways, the Network has been an integral part to ensuring that the agenda for children across the North Thames remains a critical focus within the ICBs. The relations have strengthened consistently over the last 9 months, and the partnership between the Network as ICB has produced tangible solutions to both immediate patient care problems such as elective backlog, to longer sustainable work to improve patient pathways.



As we enter a period of increased turbulence with the planned dissolution of NHS England, the role the network plays will be increasingly important to provide stability and vision for children's care across the North Thames.



Mr Nicholas Alexander
Co- Clinical Director



**North Thames
Paediatric Network**
Connecting paediatric services



NHS
Great Ormond Street
Hospital for Children
NHS Foundation Trust

NHS
England
London

SUPPORT & ENQUIRIES



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If you have any enquiries please do not hesitate to contact the Network at england.ntpn@nhs.net



Access our website via the link below for more information and resources.

<https://ntpn.co.uk/>



Instagram:
[norththamespaediatricnetwork](https://www.instagram.com/norththamespaediatricnetwork)



X (previously Twitter):
[@NTPaedsNetwork](https://twitter.com/NTPaedsNetwork)



[North Thames Paediatric Network](#)

DEVELOPMENT & CAREER OPPORTUNITIES

The Network is invested in developing those working in Children and Young People. We often have quality improvement roles for nurses which we can offer on a fixed term basis or secondment. We also have project management positions and are able to support those on graduate programmes.

Please search North Thames Paediatric Network on NHS Jobs or feel free to email us at england.ntpn@nhs.net