Independent Patient Safety Investigation (IPSI) Report

Of

Yusuf Mahmud Nazir

Written by: Dr Peter Carter, OBE and
Nurture Health and Care Ltd.

Incident ID number:	YN IPSI
Date the incident occurred:	23 November 2022
Report approved date:	28 July 2025
Approved by:	NHS England, NPSIIT

Distribution List

Name	Position
Family of Yusuf	Mother, Uncle & Legal Representative
NHSE National Patient Safety Independent Investigation Team (NPSIIT)	Head of NPSIIT
NHSE North East and Yorkshire Regional Team	Regional Director of Nursing & Clinical Quality Director
South Yorkshire Integrated Care Board	Chief Executive
The Rotherham NHS Foundation Trust	Chief Executive
Sheffield's Children's NHS Foundation Trust	Chief Executive
The GP Surgery	Practice Manager
Yorkshire Ambulance Service NHS Trust	Chief Executive

Disclaimers

Confidentiality, Anonymisation and Use of Source Material

The report has been fully anonymised to remove all names and identifiable information of staff across the healthcare settings involved. However, at the request of the family, the name of the patient and the names of family members, where referenced in their statements or narrative contributions, have been retained.

Where information in this report appears in italics, it indicates a direct excerpt from an original source of evidence or from the original Expert's investigation report.

This investigation has not conducted a forensic examination of any digital material, including clinical systems or social media platforms, as such analysis falls outside the scope and expertise of this investigation. All evidence presented has been collected through standard investigative procedures and included as discovered during our lines of enquiry.

The methodology involved systematic collection and review of available evidence, ensuring that all material was documented accurately and impartially. We have considered all evidential material comprehensively to establish a clear timeline and to understand the perspectives of individuals involved.

This approach ensures an objective and transparent process, providing a factual basis for the findings without extending into specialised forensic analysis beyond the scope of this investigation.

Statement on the Inclusion of WhatsApp Messages

We acknowledge the family's request for the full WhatsApp message history to be appended to the final report. However, after careful consideration, the decision has been made not to include these messages in their entirety.

This decision is rooted in our responsibility to uphold legal, ethical, and professional standards, including those outlined in the UK General Data Protection Regulation (UK GDPR), Caldicott Principles, and broader duties of confidentiality and proportionality. While the WhatsApp messages form a valuable part of the family's narrative, their full publication raises significant concerns—particularly regarding the inclusion of sensitive material, references to third parties, and images of Yusuf during his final days.

Instead, evidential material from the WhatsApp messages has been selectively and purposefully used throughout the investigation report to support contextual analysis, triangulate timelines, and illustrate thematic findings. This approach ensures that the family's lived experience is acknowledged and meaningfully integrated, while safeguarding the dignity of Yusuf and maintaining fairness for all involved parties.

We recognise that this decision differs from the family's expressed wishes. However, we believe it represents a proportionate, ethical, and lawful balance between transparency, respect, and the integrity of the investigation

Contents

About Patient Safety Investigations

Independent Patient Safety Investigations (IPSI) are undertaken to identify new opportunities for learning and improvement. IPSIs focus on improving healthcare systems; they do not look to blame individuals. Other organisations and investigation types consider issues such as criminality, culpability or cause of death. Including blame or trying to determine whether an incident was preventable within an investigation designed for learning can lead to a culture of fear, resulting in missed opportunities for improvement.

The key aim of an IPSI is to provide a clear explanation of how an organisation's systems and processes contributed to a patient safety incident. Recognising that mistakes are human, IPSIs examine 'system factors' such as the tools, technologies, environments, tasks and work processes involved. Findings are then used to identify actions that will lead to improvements in the safety of the care patients receive.

The investigation team followed the Duty of Candour and the Engaging and involving patients, families and staff after a patient safety guidance in their collaboration with those affected, to help them identify what happened and how this resulted in a patient safety incident. Investigators encourage human resources teams to follow the Just Culture guide in the minority of cases when staff may be subject to an investigation interview or asked to participate.

This independent patient safety investigation (IPSI) is Chaired by an experienced investigator who is trained to conduct investigations for learning. All of the associated team and Experts follow the guidance set out in the Patient Safety Incident Response Framework and in the national Patient Safety Incident Response standards.

A Note of Acknowledgement

Nurture Health and Care and Peter Carter extend our deepest gratitude to all who contributed to this investigation. Most notably, we recognise the family of Yusuf, whose courage, openness, and willingness to share their experiences have been invaluable in this process. The death of any child or young person is incredibly difficult, and when that death is linked to infection, it often raises many questions. Each child is a precious individual, and their loss is a profound tragedy for parents, siblings, grandparents, carers, guardians, extended family, and friends.

We also extend our sincere thanks to the dedicated healthcare professionals and organisations involved in Yusuf's care, including the GP surgery, The Rotherham NHS Foundation Trust (TRFT), Yorkshire Ambulance Service NHS Trust (YAS), Sheffield Children's NHS Foundation Trust (SCH), South Yorkshire Integrated Care Board (ICB), and NHS England's national patient safety team. Your engagement, transparency, and commitment to learning and improvement have been instrumental in this investigation.

Yusuf Mahmud Nazir was described as a bright, loving, and well-mannered five-year-old boy from Rotherham, loved and cherished by his family, friends, and local community. Known for his kindness, intelligence, and competitive spirit, he was deeply adored by his parents, two elder brothers, and extended family, with whom he shared a close-knit bond.

> "*The unimaginable loss of Yusuf has left all his family heartbroken with a feeling of emptiness that can never be filled. Yusuf's energy, mannerisms and infectious smile will forever be missed by everyone he came in contact with.*" – Shared by Yusuf's family

Yusuf's passing at such a young age is an immeasurable loss. He was a child full of potential, whose warmth, humour, and ambition left a lasting impact on all who knew him.

Chair's Overview

The loss of a child is an unimaginable tragedy. Its impact on parents and family runs deep, and while the intensity of grief may lessen over time, the absence will always resonate, leaving an enduring memory and unwavering love for the child.

Family gatherings, birthdays and other milestones will be a poignant reminder of a life cut short.

Our investigation into the death of Yusuf is one of the saddest assignments that myself and the team from Nurture Health and Care, together with our experts have been involved in.

Throughout, we have been moved by the love and affection Yusuf's family have shown towards him and we fully empathise with their wish to have a further understanding of his journey from the first visit to the GP practice to the time of his death in Sheffield Children's Hospital.

We hope our report will answer many of their questions and concerns.

We also wish to record that we have had full cooperation from The Surgery, YAS, TRFT and SCH. All the staff we have interviewed and met with have expressed their sadness over Yusuf's death, many of whom have been significantly distressed by this tragic event.

If Yusuf's death is not to be in vain, we hope that the lessons learnt, and our recommendations will be fully accepted and that the organisations involved will continue to monitor their implementation.

Dr Peter Carter, OBE.

Biography of Yusuf *provided by the Family*

Full Name: Yusuf Mahmud Nazir

Date of Birth: 12.08.2017

Date of Passing: 23.11.2022

Age: 5 years old

Place of Residence: Rotherham

Yusuf was a happy, healthy and bright child, adored by all his family and friends. He was well known as being 'the perfect child', always wanting to be the best in everything he did. Yusuf was always praised by his family for being amazing in every way possible. He would often surprise people with his politeness, manners, and sensible behaviour for a boy of his age. Yusuf was close to his grandparents, aunts, uncles and cousins. We are a close-knit family and would see each other most days. The entire family adored Yusuf.

Yusuf was also loved by the local community whom he would chat with whilst on his regular scooter rides with his dad.

Yusuf lived with both his parents and 2 elder brothers Rehaan (10 years older to him) and Shoaib (5 years older to him).

Yusuf shared a special bond with Shoaib. Yusuf would rank his parents and brothers in order of who he loved the most, which made us laugh. He would begin by expressing his love for Shoaib, saying "Shoaib is zero, because zero comes before 1", and then the rest would follow.

Yusuf enjoyed his family tradition of going to get his favourite fresh doughnuts from a cafe every Friday. He had an amazing time in Cyprus on our family holiday where he celebrated his 5th birthday, and was eagerly looking forward to go again the following summer.

Spending time with his mummy, daddy and brothers was his most favourite thing to do, and where he felt the most confident and happiest. He knew he was the king of the house.

He loved going on bike rides with his family or taking a walk and going to playgrounds and parks.

The family share their pride of Yusuf's accomplishment of learning to fluently read Arabic just before he died. He learnt to read Arabic in only 4 months and was very proud of himself. "That was our bright Yusuf". He was very competitive and would keep a close eye on what page his cousin was on, just in case he beat him. Yusuf had so much potential, and a very bright future ahead.

Although born and brought up in South Yorkshire, Yusuf had a strong American accent that he picked up from an American children's programme he liked to watch. The way he spoke was loved by all his family, who until today still fondly imitate him when speaking about him.

Yusuf was a Year 1 pupil at his Primary School, where he was deeply loved and valued by both his teachers and peers. He was described as a quiet but happy child, always eager to please and determined to do his best in everything he did. Yusuf was a positive role model, known for his kindness, strong friendships, and enthusiasm for learning—particularly excelling in Mathematics and creative activities. His teachers fondly recalled his sparkling eyes, bright smile, and love for football and Peter Rabbit.

A letter was provided to the IPSI Family Liaison Lead by the school, highlighting Yusuf's positive impact on the school community and the many ways in which his memory continues to be honoured. This includes a photograph displayed in the school entrance, the dedication of a planter in the school yard, and the school's participation in an annual memory run. The school community continues to celebrate his life by wearing blue—his favourite colour—or dressing as rabbits in honour of his love for Peter Rabbit.

Executive Summary

INCIDENT OVERVIEW

The investigation was commissioned by NHS England in response to concerns raised by the family regarding the care and treatment of Yusuf across multiple clinical settings, before his death on 23rd November 2022.

Yusuf's family raised the following concerns;

- Care and treatment received at the The Surgery General Practice surgery on 15th and 18th November 2022
- Care and treatment received during attendance at TRFT Emergency Department on 15 – 16 November 2022.
- Care and treatment received during admission at SCH on 18 November – 23 November 2022.
- Care and treatment received by YAS on 18 November 2022.

SUMMARY OF KEY FINDINGS

Although there is agreement that Yusuf had pneumonia and sepsis, which led to respiratory failure and his death, there was no causative agent which could be found on laboratory testing. It is impossible to make a statement on whether IV antibiotics or earlier detection would have prevented Yusuf's death.

We understand that this is not the information that the family obtained initially and appreciate how this difference of professional opinion has led to confusion and emotional distress for the family.

Yusuf's death followed a prolonged and traumatic resuscitation attempt, and the impact underscored the emotional and psychological toll on both the family and professionals involved.

Our primary finding is that the parental concerns, particularly the mother's instinct that her child was unwell, were repeatedly not addressed across services. A reliance on clinical metrics over caregiver insight caused distress for the family. This led to a lack of shared decision-making and there was limited evidence of collaborative discussions with Yusuf's family around clinical decisions, leading to a sense of exclusion and reduced trust in care plans.

Yusuf had 23 separate healthcare contacts, across four organisations with no single, coordinated record or oversight, contributing to fragmented and disjointed care. Many of the healthcare professionals acted primarily in triage roles which diminished parental voices.

Inconsistent clinical assessment of the respiratory system of tonsilitis and between organisations and minimal references to differential diagnosis, meant while some vital signs were recorded, the clinical assessments were inconsistent leading to difficulties in comparing Yusuf over time, with insufficient interpretation of parameters such as respiratory rate and oxygen saturation and a focus on tonsillitis to the exclusion of alternative explanations.

Areas of improvement were raised about the care and treatment of Yusuf during admission to Sheffield Children's Hospital from the 18th to the 23rd November 2022 in relation to in cannula care and maintenance, medication administration and poor documentation, the use of Paediatric Early Warning Scores (PEWS), and missed opportunities to escalate with lack of visibility of consultant oversight. This occurred over a weekend, highlighting the reduced resourcing often seen during this period, including limited workforce availability and fewer senior decision-makers, which is a challenge recognised nationally.

While the response to acute deterioration was excellent and substantive, routine care prior to crisis was marked by a 'wait and see' approach that failed to pre-empt worsening symptoms.

The Surgery on 15th and 18th November 2022, TRFT Emergency Department on 15 – 16 November 2022 and YAS on 18th November 2022 treatment were in line with clinical guidelines and treated in line with Yusuf's presentation at that time.

SUMMARY OF AREAS FOR IMPROVEMENT AND SAFETY ACTIONS

Nurture Safety Bridging Statements

This investigation has been grounded in the principles of systems-based learning, Just Culture, and Psychological Safety, rather than generating solely procedural recommendations, the findings embrace Nurture's Safety Bridging Statements.

Organisations are encouraged to use these questions as starting points for internal enquiry, reflection, and conversation. Whether through multidisciplinary forums, reflective practice sessions, or governance meetings, teams can use them to co-design local safety actions and recommendations that are grounded in lived experience and context:

- How might care change if we treated a caregiver's intuition not as an adjunct, but as a legitimate and vital form of evidence? What becomes possible when the instinct of a mother is given the same attention as a monitor reading?
- How can our systems which were built to triage risk, uphold advocacy as an act of care, even when resources are limited?
- We recommend that systems of governance move beyond procedural assurance and incorporate reflective, trauma-informed practices that acknowledge the emotional labour of care and moral injury.

This includes:

- Recognising trauma as a legitimate influence on decision-making, behaviour, and team dynamics.
- Embedding reflective space within governance structures, not outside of them.
- Asking not just what went wrong, but what was the emotional cost and how do we learn and support each other?

RECOMMENDATIONS

Detailed CREATED SMART recommendations are provided at the end of this report and are summarised here by thematic area.

1. **GENERAL RECOMMENDATIONS *(Applicable Across All Areas)***

    - Improve recognition of documentation of differential diagnosis
    - Systematically embed caregiver concerns into clinical assessment and decision-making.

2. **THE ROTHERHAM NHS FOUNDATION TRUST (TRFT) RECOMMENDATIONS**

    - Introduce structured documentation protocols for recording parental concerns.

3. **YORKSHIRE AMBULANCE SERVICE (YAS) RECOMMENDATIONS**

    - Address the impact of work pressures, including rest breaks and downtime.
    - Strengthen cultural competence, psychological safety, and civility in practice.
    - Clarify processes around patient choice and communication.

4. **SHEFFIELD CHILDREN'S HOSPITAL (SCH) RECOMMENDATIONS**

    - Implement comprehensive vascular access guidelines, including cannula insertion and fixation
    - Conduct a medicines management policy review.
    - Review and standardise the prescription chart format.
    - Enhance PEWS training, with clear escalation pathways.

5. EXPERT-LEVEL RECOMMENDATIONS

Support NIHR research into:

- NIHR Research: How caregiver concerns are raised, received, and acted upon.
- NIHR Research: Tonsillitis complications and the management of secondary infections

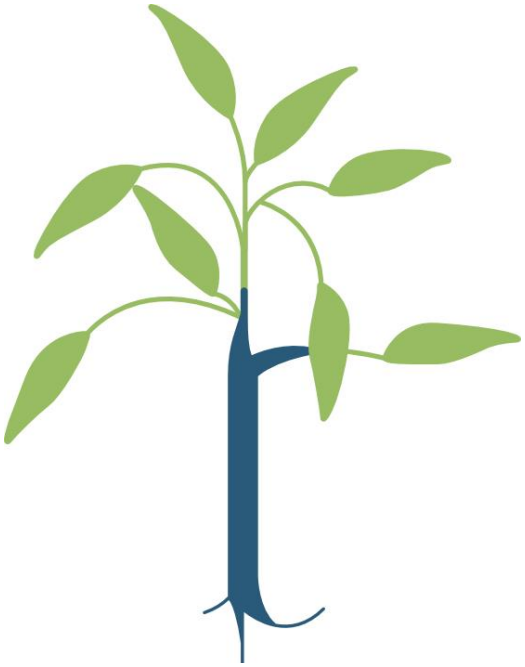
6. FAMILY-REQUESTED RECOMMENDATIONS

- To ensure families are informed that when their children are on ventilators, they may still be able to hear, and should be encouraged to talk to and interact with them
- To ensure that any items such as clothing or equipment can be saved so families can keep as memories when a child dies.

7. NATIONAL RECOMMENDATIONS *(which are not considered SMART but intended to inform wider system improvement):*

- **Consultant Oversight**: Explore a national workforce plan to support sustainable consultant-led oversight, including realistic weekend cover models in paediatrics.
- **Parental Access to Records**: Consider national guidance on giving parents visibility of their child's medical records during admission, similar to maternity-held notes.
- **Paper Record Use**: Review the continued use of paper-based records in paediatric care, due to potential risks to continuity and safety.

Background and Context



Background and Context

The death of a child is a profound tragedy, impacting families, communities, and society at large. Understanding the circumstances surrounding such deaths is essential for developing effective prevention strategies, improving healthcare systems, and ensuring comprehensive support for affected families. In England, the National Child Mortality Database (NCMD) plays a pivotal role in collecting and analysing child mortality data to inform national policy and healthcare practices.

According to the NCMD's "Child Death Review Data Release: Year Ending 31 March 2024[1]" there were 3,577 child deaths in England, equating to a mortality rate of 29.8 per 100,000 children. While this represents a 4% decrease from the previous year, it remains higher than pre-pandemic levels observed in 2019-2020.

Disparities in Child Mortality

Significant regional, ethnic, and socioeconomic disparities persist:

- **Regional Variance:** Mortality rates ranged from 24.2 to 40.7 per 100,000 children across different regions.
- **Ethnic Disparities:** Children of Black or Black British ethnicity had the highest death rate (55.4 per 100,000), followed by Asian or Asian British ethnicity (46.8 per 100,000). Over a five-year period, children of Asian Pakistani ethnicity had a mortality rate of 57.0 per 100,000, more than double that of White British children (22.9 per 100,000).
- **Socioeconomic Factors:** Children from the most deprived areas had a death rate of 42.9 per 100,000, compared to 17.2 per 100,000 in the least deprived areas.

These disparities highlight the urgent need for equitable healthcare access and targeted interventions to address underlying social determinants of health.

Healthcare Workforce Challenges

The healthcare system faces significant challenges in providing timely and adequate care for children and families, with workforce shortages across key sectors leading to delays, fragmented care, and increased clinical risk.

[1] https://www.ncmd.info/publications/child-death-review-data-release-2024/

Paediatric Workforce Shortages

- The NHS vacancy rate was 8.4% (121,000 roles unfilled) as of September 2023 (*The King's Fund*[2]).
- The Royal College of Paediatrics and Child Health (RCPCH)[3] reports nearly 1 in 5 consultant paediatric posts remain unfilled due to a lack of suitably qualified candidates.
- High levels of burnout, unsustainable workloads, and emotional exhaustion are further exacerbating these shortages.

General Practitioner Crisis

- As of November 2024, there were 28,139 fully qualified GPs in England—a reduction of 1,226 since 2015 (*BMA*)[4].
- The average GP now cares for 2,056 patients, representing a 10% increase since 2015.

Impact on Services

- Workforce shortages strain emergency departments, ambulance services, and community care.
- Delays in escalation can result in missed opportunities for early intervention.
- Burnout among healthcare professionals reduces clinical vigilance, increasing the risk of adverse outcomes.
- Role of media, especially social media on the morale of staff[5]

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[2] http https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice-data-analysis#:~:text=As%20of%20December%202024%2C%20there%20were%2038%2C626,equates%20to%2028%2C197%20full%2Dtime%20fully%20qualified%20GPs.s://www.kingsfund.org.uk/insight-and-analysis/data-and-charts/staff-shortages

[3] https://www.rcpch.ac.uk/sites/default/files/2019-11/RCPCH%20Election%20Workforce%20manifesto%202019%201.4.pdf

[4] https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice-data-analysis#:~:text=As%20of%20December%202024%2C%20there%20were%2038%2C626,equates%20to%2028%2C197%20full%2Dtime%20fully%20qualified%20GPs.

[5] https://pmc.ncbi.nlm.nih.gov/articles/PMC4103576/

National Policy and Strategic Framework

Over the past two decades, the NHS has faced significant workforce shifts in clinical roles. These changes including shortages of experienced staff, increased use of support workers, and evolving skill mix including consistency of service across all days of the week raising concerns about patient safety and care quality[6] (Appendix 10)

The RCPCH Blueprint: From Left Behind to Leading the Way[7] outlines a strategy to prioritise child health across seven key areas:

1. Funding
2. Workforce
3. Integration
4. Data and Digital Innovation
5. Urgent and Emergency Care
6. Community Services
7. Primary Care

The Government's NHS Workforce Plan[8] also aims to address workforce gaps, improve retention, and enhance service delivery through initiatives such as Primary Care Transformation and the development of a "Neighbourhood Health Service."

Evidence Base for Child Mortality and Infections

Investigations and national reviews provide critical insights into the risks associated with diagnostic delays and fragmented care pathways:

- NCEPOD "Just Say Sepsis!" (2015)**[9]:** Highlighted delays in recognising sepsis, inadequate early warning systems, and insufficient senior clinician involvement.

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[6] https://www.nuffieldtrust.org.uk/resource/the-nhs-workforce-in-numbers#:~:text=The%20clinical%20support%20workforce%20are,training%20and%20development%20to%20all

[7] https://www.rcpch.ac.uk/sites/default/files/2024-09/rcpch_child_heath_blueprint_2024.pdf

[8] https://www.england.nhs.uk/publication/nhs-long-term-workforce-plan/

[9] National Confidential Enquiry into Patient Outcome and Death (NCEPOD). (2015). Just Say Sepsis! A review of the process of care received by patients with sepsis. Available at: https://www.ncepod.org.uk/2015report2/downloads/JustSaySepsis_FullReport.pdf

- NCMD Thematic Report on Infection-related Deaths[10]**:** Underscored the need for early recognition, timely treatment, and effective escalation of care for severe paediatric infections.
- Coroner Findings**:** Preventable outcomes linked to missed opportunities for timely intervention.
- In Nov 2022, at the time of the illness, there was a significant outbreak of Group A Streptococcus, a type of bacteria that can cause a range of infections across the UK[11] leading to significant pressure across the whole system with unprecedented levels of children's attendances at Emergency Departments.

These findings advocate for improved clinical guidelines, enhanced training for healthcare professionals, and robust early warning systems to address diagnostic and care pathway failures.

Systemic Challenges in Patient Flow and Care Delivery

The involvement of multiple teams with different areas of expertise is often necessary for delivering complex, end-to-end care but in a complex eco-system of healthcare emphasis on patient flow metrics can overshadow a holistic approach:

- Task-Oriented Approach**:** Healthcare staff, face pressures to meet efficiency targets, which may compromise patient advocacy and personalised care.
- Evidence Based Care: Focuses on those that are average, amplifies the mean and possibly leads to those 'outliers' not receiving the individualised care they need.
- Fragmented Systems: Multiple touchpoints (GPs, NHS 111 and 999, ambulance services, Emergency Departments and paediatric wards) create communication and continuity gaps requiring effective handover and co-ordination of care.
- Loss of Experience**:** Rapid career progression, staff turnover, and burnout contribute to a loss of institutional knowledge and expertise.
- Trauma: embedded and impacting decision-making.
- Pneumonia in Children is rare: The presentation of life-threatening pneumonia is unusual in children and therefore clinical teams focus on those conditions which were more likely.

[10] https://www.ncmd.info/wp-content/uploads/2023/12/Infection-related-deaths-of-children-and-young-people-in-England.pdf

[11] UKHSA update on scarlet fever and invasive group A strep - GOV.UK

Rights and Ethical Considerations

Under the United Nations Convention on the Rights of the Child (UNCRC)[12], every child has the right to healthcare of the highest attainable standard. Inequities in healthcare access, diagnostic delays, and inconsistent adherence to NICE guidelines (e.g., NG51 for Sepsis[13], NG84 for Tonsillitis[14], CG191 for Pneumonia[15]) can breach these principles.

The "Listening to You" communication bundle[16] is an initiative designed to enhance communication between healthcare providers and parents or carers in paediatric settings. Its primary goal is to ensure that parental concerns are heard and addressed promptly, thereby improving patient safety and quality of care.

One notable implementation of this initiative is at Birmingham Women's and Children's NHS Foundation Trust[17]. They have established a structured process that encourages parents to voice their concerns and outlines clear steps for escalation if they feel their child's condition is not being adequately addressed. This includes direct access to the Paediatric Assessment & Clinical Escalation (PACE) team when necessary. This has also been introduced more recently at Sheffield Children's Hospital.

In terms of recent developments, NHS England has introduced the "Listening Well Guidance," published in February 2023[18]. This document provides a framework for NHS organisations to develop local listening strategies, emphasising the importance of understanding and improving experiences to ultimately enhance patient care.

Martha's Rule and Family-Centred Care

The introduction of Martha's Rule emphasises the critical role of families in advocating for their child's care:

- Provides families with a formal mechanism to escalate concerns.

[12] https://www.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf#:~:text=The%20States%20Parties%20to%20the%20present%20Convention%2C&text=States%20Parties%20recognize%20the%20right%20of%20the,of%20access%20to%20such%20health%20care%20services.

[13] https://www.nice.org.uk/guidance/ng51

[14] https://www.nice.org.uk/guidance/ng84

[15] https://www.nice.org.uk/guidance/cg191

[16] https://www.england.nhs.uk/patientsafety/wp-content/uploads/sites/32/2015/03/parents-leaflet2.pdf

[17] https://bwc.nhs.uk/listening-to-you/

[18] https://www.england.nhs.uk/long-read/listening-well-guidance/

- Ensures visible access to critical care teams.
- Acknowledges parents as experts in their child's condition and experience.

This aligns with the principle: "Doctors should see the parent as the expert on that child."

Healthcare Oversight and Integrated Care

Current healthcare systems lack whole-system oversight, with fragmented services preventing a unified narrative of a child's healthcare journey.

- The RCPCH advocates for a digital child health record to improve information sharing and reduce fragmented care[19].
- Evidence from BMJ Quality & Safety[20] highlights diagnostic errors stemming from communication breakdowns and siloed care delivery.
- The Medical Examiner (ME) system[21] was introduced as part of national efforts to improve the quality and transparency of death certification, enhance patient safety, and support bereaved families. The role was developed in response to failures in mortality review systems and recommendations from high-profile inquiries.

The Role of the Coroner in Child Death Investigations

The coroner is responsible for investigating deaths that are:

- Sudden, unexpected, or unexplained.
- Violent or unnatural.
- Occurring in state detention (e.g., police custody or prison).
- Where the cause of death is unknown.

When a child dies, the coroner must be notified if any of the above criteria apply. The investigation aims to determine:

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[19] https://www.rcpch.ac.uk/sites/default/files/2024-09/rcpch_child_heath_blueprint_2024.pdf

[20] https://qualitysafety.bmj.com/content/33/12/823

[21] https://www.england.nhs.uk/patient-safety/medical-examiners/the-national-medical-examiner-system/#:~:text=Since%209%20September%202024%2C%20all,Social%20Care's%20Death%20Certification%20Reforms.

1. Who the deceased was.
2. When and where the death occurred.
3. How, including in some cases in what circumstances, the death happened.
4. Whether a post-mortem or inquest is required.

The Post-Mortem Examination Process

A post-mortem may be ordered by the coroner to establish the cause of death.

- If a natural cause of death is identified, the coroner may close the investigation.
- If the cause of death is unclear or suspicious, an inquest may be opened.

A post-mortem is essential in identifying unknown causes of death, detecting undiagnosed medical conditions, and providing crucial answers for bereaved families.

The statutory requirement for medical examiners to independently scrutinise all non-coronial deaths in England and Wales was implemented on 9 September 2024 and therefore was not in place in 2022 however the Medical Examiner (ME) role was introduced to improve death certification, patient safety, and transparency in the mortality review process. MEs provide independent oversight of deaths that do not require a coroner's referral and ensure that families have a clear explanation of their loved one's cause of death.

In child deaths where the cause is unclear, a post-mortem is critical to:

- Identify hidden or rare medical conditions.
- Detect infections, genetic disorders, or metabolic diseases that were previously undiagnosed.
- Provide essential information for family genetic counselling.
- Determine if systemic failures or medical errors contributed to death.
- Ensure justice in cases of abuse, neglect, or medical malpractice.

Care Quality Commission (CQC) Findings Across Key Services

The Surgery, Rotherham

- **Inspection Date:** 6-7 December 2022 | **Report Published:** 11 January 2023
- **Ratings:** Safe – *Requires Improvement* | Effective – *Good* | Caring – *Good* | Responsive – *Good* | Well-led – *Good*
- Full report: CQC Surgery Inspection Summary

From the Practice Manager and the team statement of improvement in relation to the previous investigation;

As medicine continues to evolve, we are committed to continuous learning while ensuring that patient care remains our top priority. In response, we have implemented several measures to enhance patient safety and clinical support:

- *A locum pack is now readily available for all locum GPs, ANPs, and any clinician seeing patients. This is updated regularly as needed when information changes.*
- *Paediatric pulse oximeters have been placed in all consultation rooms, with additional infant and neonatal pulse oximeters available in the treatment room.*
- *Paediatric consultations are now documented using the Ardens templates to ensure comprehensive and structured record keeping.*
- *We have reinforced an open-door policy, with a clinician (GP) available from 8:00 AM to 6:30 PM. This extends to all staff, including locum GPs and ANPs, ensuring they can seek guidance whenever needed.*

It was also acknowledged that The Surgery has an action plan in place that all professionals had to state their role and professional registration.

We are also proud to share that, in the 2023 GP Patient Survey, The Surgery was ranked among the top 10 most improved practices in the Northeast and Yorkshire region-a testament to our ongoing efforts to enhance patient care.

Yorkshire Ambulance Service NHS Trust

- **Inspection Date:** 28 May–28 June 2019 | **Report Published:** 14 October 2019
- **Ratings:** Safe – *Good* | Effective – *Good* | Caring – *Good* | Responsive – *Good* | Well-led – *Good*.
- Full report: CQC Yorkshire Ambulance Service Report

Yorkshire Ambulance Service NHS Trust and their statement of improvement in relation to the previous investigation.

Yorkshire Ambulance Service NHS Trust (YAS) has confirmed its strong commitment to fostering a learning ethos that prioritises patient safety. YAS has developed a comprehensive Patient Safety Incident Response Plan (PSIRP) to address and learn from patient safety incidents effectively. This plan focuses on identifying patient safety themes.

In response to Yusuf's case, and specifically the identification and management of sick children, YAS has taken proactive measures to incorporate this critical topic into its clinical training programmes. All frontline clinical staff are mandated to attend an annual Clinical Refresher training day. This training includes modules on recognising clinical deterioration in children and the identification and management of sepsis. This training utilises tools such as the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) guidelines, informed by the National Institute for Health and Care Excellence (NICE) Traffic Light system and the Paediatric Sepsis Screening Tool to aid effective decision-making.

To further aid learning, YAS supports staff with clinical supervision, to enhance professional development and continuous learning to support high-quality patient care. The clinical supervision takes the form of patient case-based discussions with peers and senior clinicians. This further promotes the ethos of continual learning and professional development.

Sheffield's Children's NHS Foundation Trust

- **Inspection Period:** October 2017 – September 2018
- **Ratings:** Overall – *Good*
- Full report: CQC Sheffield Children's Hospital Report

Sheffield Children's Hospital and their statement of improvement in relation to the previous investigation.

This is a summary of an extensive document provided by Sheffield Children's Hospital where they state that:

'*Learning is positioned as a core characteristic of the organisation's culture. We value and encourage learning from our own experiences, but also look beyond ourselves for lessons, and avoid complacency through actively seeking learning opportunities, the 'could have been better if' moments, rather than only learning from what has already happened.*

As part of this continual journey, we have moved from transactional approaches which focus on knowledge transfer and completing tasks, to a transformational one emphasising personal growth, critical thinking, a systems approach and adapting to new situations. Any lessons learned are embedded into our culture and practices, enabling truly effective learning and sustainable service improvement'.

- *Our escalation procedures for deteriorating patients have been significantly refined. A refreshed escalation policy clearly communicates the importance of timely and effective escalation of clinical concerns, supported by our Parent and Carer Escalation Pathway (PaCE). The structured SBAR communication method ensures clarity between referring and receiving parties, enabling prompt decision-making and care delivery.*
- *We have standardised the Paediatric Early Warning Score (PEWS) system across clinical environments through digital integration via the CareFlow Connect app. Recognising the limitations of PEWS, our guidelines highlight the importance of both parental insight and clinical intuition in identifying deterioration, encouraging vigilance beyond numeric scores. Additionally, initiatives such as the Sepsis Lead Nurse programme reinforce proactive identification and early intervention strategies.*
- *Intravenous (IV) practices have been comprehensively reviewed, revitalising fundamental care standards. Updated cannula care guidelines, annual IV competency assessments, and the re-established IV Practice group promote evidence-based practices, with consistent auditing and reporting through the Nursing Care Quality Indicators Dashboard.*

Overall, our culture value openness, learning from challenges, and proactively improving services rather than assigning individual blame, ensuring sustainable service quality and patient safety.

The Rotherham NHS Foundation Trust

- **Inspection Period:** March 2020 – February 2021
- **Ratings:** Overall – *Requires Improvement*
- Full report: CQC Rotherham General Hospital Report

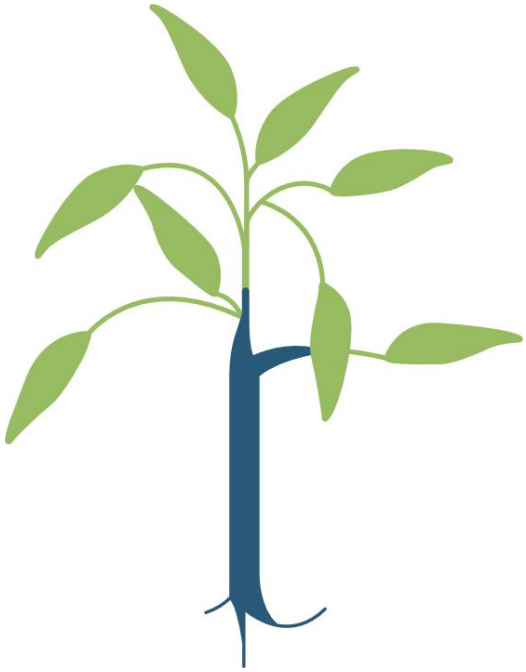
Rotherham General Hospital and their statement of improvement in relation to the previous investigation.

Building on the recommendations made a number of actions were taken which included;

- *Simulation training that incorporated scenarios where both medical and nursing staff are able to work through how to manage challenging situations and conversations thus further supporting staff to respond with compassion and empathy.*
- *A Trust wide communication was circulated to re-iterate the importance of listening and responding to concerns raised by parents or relatives.*

- *A programme of works was undertaken to ensure that medical staff roles are updated with in the Electronic Patient Record (EPR) to ensure that there is accurate recording of medical staff grades within EPR.*
- *A communication was circulated to the relevant staff groups re-iterating that growth charts are held within Meditech and they are to be completed in line with national guidance.*
- *Digital systems were reviewed and alterations made to ensure that it is easily identifiable as to which Early Warning Scoring tool has been used.*
- *A QR code for the Healthier Together Online resource was displayed in Urgent Emergency Care Centre (UECC) and paper copies of the relevant section can be printed on request. Staff within the paediatric UECC received an e-mail communication raising awareness of the Healthier Together website.*

Description of The Patient Safety Incident & Investigation Approach



Description of The Patient Safety Incident

This investigation is commissioned by NHS England in response to concerns raised by the family regarding the care and treatment of Yusuf across multiple clinical settings, before his death on 23rd November 2022.

Yusuf's family have raised concerns regarding;

(1) Care and treatment received at The Surgery on 15th and 18th November 2022
(2) Care and treatment received during attendance at TRFT Emergency Department on 15 – 16 November 2022.
(3) Care and treatment received during admission at SCH on 18 November – 23 November 2022.
(4) Care and treatment received by YAS on 18 November 2022.

It is noted that the health status of Yusuf as a child before the acute episode in 2022 is outside the Terms of Reference and, if felt appropriate to review, this would require the Terms of Reference extending.

This IPSI is being conducted to address the family concerns and evaluate how parents contributed to decision-making in medical contexts.

Investigation Approach

Key workstreams addressed specific areas of concern raised by Yusuf's family; involving expert-led reviews across multiple aspects of care, communication, and policy adherence.

Each report from the expert/workstream lead accompanies this report as an appendix.

Investigation team

Role	Name	Position	Organisation
Investigation Chair:	Dr Peter Carter	IPSI Chair	Independent Management Consultant
Clinical Experts:			
Prof Damian Roland		Specialist in Paediatric Emergency Medicine	
Dr Elizabeth Whittaker		Specialist in infectious diseases	
Sara Melville		Nurse Consultant in Paediatric Vascular Access	
Anneliese Hillyer-Thake		Paramedic Expert, Independent Investigator/Clinical Reviewer	Nurture Health and Care Ltd
Jackie Furlong		Workforce Analysis, Independent Investigator / Clinical Reviewer	Nurture Health and Care Ltd
Thematic and Risk Analysis Lead:	Prof Vanessa Webb	Medical Director	Nurture Health and Care Ltd
Family Liaison and Workforce Support:	Shaney-Ann Charles	Exec Director of Workforce	Nurture Health and Care Ltd
Review of CCTV:	Paul Jennings	Operations Director	Nurture Health and Care Ltd
Investigation Operations Lead:	Taymika Brandy	Operations Manager	Nurture Health and Care Ltd
Staff Engagement Lead:	Sarah Griffin	Patient Safety Coordinator	Nurture Health and Care Ltd

The Perspectives of the Family

Introduction

This investigation was commissioned by NHS England in response to concerns raised by Yusuf's family. The concerns related to the care and treatment Yusuf received, across multiple clinical settings. The investigation aligns with the terms of reference, ensuring that the family remains central to the process and is meaningfully involved throughout.

Context and Background

Yusuf's family expressed concerns regarding the care and medical treatment provided by The GP surgery, The Rotherham NHS Foundation Trust (TRFT), Yorkshire Ambulance Service NHS Trust (YAS) and Sheffield Children's NHS Foundation Trust (SCHFT).

In addition to concerns regarding clinical care, the family also raised issues related to decision-making authority structures and the publication of a report stemming from a previous investigation into the circumstances surrounding Yusuf's death in 2023. The Independent Patient Safety Investigation (IPSI) team made it clear to the family that this current investigation is not a re-examination or re-opening of the previous investigation, nor is it intended to validate or undermine the prior investigative process. Rather, it is a response to the family's expressed concerns about not feeling heard and a commitment to ensuring their active involvement in this investigation.

The Terms of Reference for this investigation (Appendix 16) were co-produced in collaboration with the family and relevant stakeholders. As such, this investigation is distinct in its scope and purpose and separate from the framework of the previous commission.

This independent investigation therefore seeks to:

- Address the family's stated concerns;
- Examine the extent to which the parents were involved in medical decision-making;
- Evaluate systemic factors that may have influenced the delivery of care;
- Review all relevant evidential material, including that previously submitted by the family and any new submissions, will be fully considered as part of this process.

Purpose

This section of the report is written to ensure that the family narratives, evidential materials provided by the family, and systemic recommendations are interwoven in a structured way. It is not written to replicate or contradict any of the findings from the Clinical Experts.

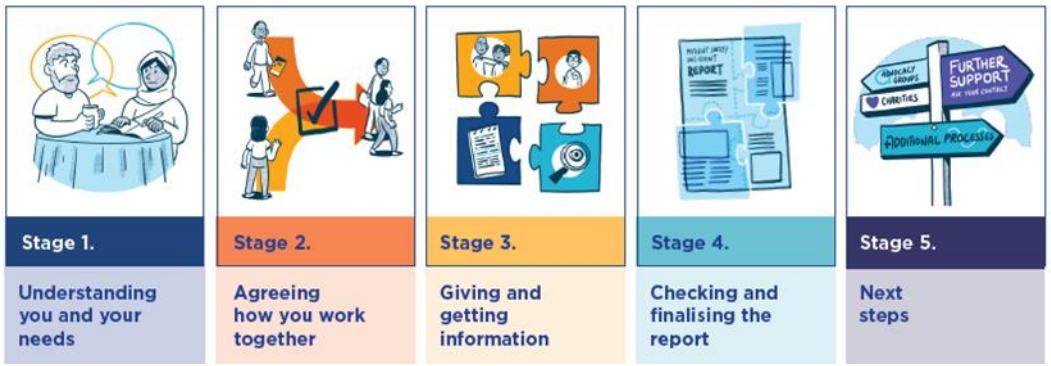
Nurture Health and Care's approach to involving families in investigations is based on our core values of Psychological Safety and evidence generated from an independent research programme called Learn Together, funded by the National Institute for Health and Care Research. The supplementary guide, designed to meet the requirements of the Patient Safety Incident Response Framework (PSIRF), was used with the family of Yusuf.

Family Liaison

All liaison with the family was led by a Director of Nurture Health and Care. A full biography was provided to the family before the engagement about the skills and background of the liaison lead, along with a confirmation that there was no conflict of interest. The Family Liaison lead was an attendee at the National Governance and Oversight meetings, ensuring that the Family's voices were represented.

The Five Stages

The diagram below describes the five-stage process that was used to meet the needs of the family and to reduce the likelihood of compounded harm.



Members of the IPSI team - Family Liaison Lead, Chair, Operations Manager and the Medical Director engaged in ten meetings with Yusuf's Mother, Paternal Uncle, and the family's legal representative to ensure that the family's voices were heard and reflected throughout the investigation process.

Overview of Meetings

Meeting 1: 16 September 2024 (in person in Rotherham)
Purpose: Understanding the needs of the Family
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI Team Representatives: Chair, Family Liaison Lead

The first meeting with the family served as an introductory session and an opportunity to establish their key points of contact within the IPSI team. In preparation for this meeting, the family was provided with the *Learn Together* guide to support their understanding of the investigation process. During the meeting, the IPSI team listened to the family's concerns, confirmed their preferred level of involvement, and agreed on a collaborative approach moving forward. This included establishing how the investigation team and the family would work together, as well as agreeing to the frequency and format of future meetings and updates.

Meeting 2: 11 October 2024 (in person in Rotherham)
Purpose: Establishing the Working Relationship and Coproduction of the Terms of Reference (ToR)
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI Team Representatives: Chair, Family Liaison Lead, Operations Manager

The focus of the second meeting was to agree on how the IPSI team and the family would work together throughout the investigation process, with particular emphasis on the family's engagement in the coproduction of the Terms of Reference (ToR). The IPSI team provided an overview of what the independent investigation involved—clarifying both its scope and limitations—drawing on the *Heads of Terms* provided by the Commissioner.

During the meeting, the family shared their lived experiences and concerns. This material was intended to inform the development of the ToR and help shape key lines of enquiry. The session provided a valuable foundation for ensuring the family's perspective was fully embedded in the design and direction of the investigation. After the meeting a bundle of evidence was provided, for review.

Further information was provided via email on 26th September 2024.

Meeting 3: 14 November 2024 (in person in Rotherham)
Purpose: Review and Factual Accuracy of the Draft Terms of Reference
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI Team Representatives: Family Liaison Lead, Operations Manager

The third meeting focused on reviewing the draft Terms of Reference (ToR) and ensuring its accuracy in reflecting the family's narrative and contributions. The written document

was shared in advance, incorporating the family's input and evidence submitted during the previous meeting.

During this session, the family's legal representative led the discussion, providing clarification on a number of key points within the document. This was to ensure that the final version of the ToR accurately captured the family's concerns, experiences, and expectations, and was aligned with the scope of the investigation. The meeting further strengthened the collaborative approach to the investigation and reinforced the commitment to transparency and accuracy.

Meeting 4: 24 February 2025 (online)
Purpose: Update on Investigation Timeline and Family Contribution to Final Report
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI Team Representative: Family Liaison Lead

During this meeting, the revised timeline for the investigation was discussed. The family were advised that the original timescales had been amended due to delays in accessing key records and evidential materials. These issues have since been resolved, allowing the investigation to progress. The appointed experts were reported to be in the process of drafting their respective reports.

The family were informed that in addition to the expert clinical analysis, a dedicated contribution from the IPSI Family Liaison Lead would be included in the final report to ensure their narrative is meaningfully and respectfully represented. The section was intended to reflect their lived experiences and the impact of events from their point of view. As part of this process, the family was invited to share any information they felt comfortable providing.

Meeting 5: 21 March 2025 (online)
Purpose: Investigation Update
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI team Representatives: Chair, Family Liaison Lead, Operations Manager, Medical Director

During this meeting, the IPSI team provided an update on the progress of the investigation. Dr Vanessa Webb, Medical Director, was introduced as the lead for the Structured Judgement Analysis (SJA) meetings and the author of the overarching report. Dr Webb's role includes synthesising the findings from all expert contributors and providing an integrated analysis to inform the final conclusions and recommendations of the investigation.

Meeting 6: 1 April 2025 (in person in Rotherham)
Purpose: Investigation Update and Response to Family Concerns
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI team Representatives: Chair, Family Liaison Lead, Medical Director

This meeting was held in person in Rotherham to provide an update on the investigation and respond to concerns raised by the family following the previous meeting on 21 March 2025. The IPSI team was able to offer reassurance that the investigation was progressing as planned, that expert engagement was ongoing, and that interviews had been requested with all relevant staff identified by the family. SCH had provided the names to two staff members who were on duty, the night recalled by the family as being involved in Yusuf's care, and steps were in place to arrange an interview as part of the investigation process.

Meeting 7: 7 April 2025 (in person in Rotherham)
Purpose: Sharing Preliminary Findings from the Investigation
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI team Representatives: Chair, Family Liaison Lead, Medical Director

This meeting was held in person in Rotherham to provide the family with an overview of the preliminary findings from the investigation. The IPSI team shared key areas of findings identified through the review and outlined where formal recommendations are likely to be made.

The family was informed that, following their review of the draft report, they would have the opportunity to provide feedback on any issues of factual accuracy. In addition, they will be invited to contribute to the formulation of recommendations, ensuring their insights and lived experience help to shape the final outcomes of the investigation.

The full draft report and the accompanying appendices were sent to the Family after the meeting for review, in preparation for the factual accuracy meeting on 11 April 2025.

Meeting 8: 11 April 2025 (in person in Rotherham)
Purpose: Review of Factual Accuracy Feedback
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI team Representatives: Chair, Medical Director

This meeting was held in person in Rotherham to review and discuss the areas of factual inaccuracy identified by the family in response to the draft investigation report. The IPSI team worked through each of the points raised, providing clarification where needed and agreeing to appropriate amendments to ensure the final report accurately reflects the events and information provided. The discussion also reaffirmed the family's ongoing involvement in shaping the final outputs of the investigation. Further points of factual accuracy were sent via email, post the meeting.

Meeting 9: 29 April 2025 (In person in Rotherham)
Purpose: To address the family's clarification about the timing of a video taken between 15 and 22 November 2022, specifically noting that the footage is recorded as 01:15 instead of the presentation in the family evidence bundle, where it is labelled: Video at 07.41
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI team Representatives: Chair, Medical Director

This meeting was held in person in Rotherham to undertake an interview with Yusuf's Mother and the IPSI team requested a statement from Yusuf's Mother to obtain a timeline, from her perspective, of the period where there were differences identified. A formal statement was sent via email, after the meeting. This statement confirmed that the video was taken at 01.15.

Meeting 10: 11 June 2025 (In person in Rotherham)
Purpose: Family requested the meeting following receipt of the draft report (v0.3)
Attendance: Yusuf's Mother, Paternal Uncle, family's legal representative.
IPSI team Representatives: Chair, Family Liaison Lead, Medical Director

This meeting was held in person at the family's request, following their receipt of the draft report titled *Overnight Clinical Oversight and Escalation in the Care of Yusuf on 20th–21st November 2022*.

The purpose of the meeting was to provide a dedicated space for the family to ask questions, express concerns, and seek clarification regarding the content of the report.

The IPSI team responded to each of the family's queries and reconfirmed the planned next steps, including the timeline and milestone dates for the completion of the factual accuracy process and the submission of the final report, to the Commissioners; NHS England.

Support for Staff

As part of our commitment to a psychologically safe and trauma-informed approach, the IPSI team offered structured staff support sessions to both The Rotherham NHS Foundation Trust (TRFT) and Sheffield Children's NHS Foundation Trust (SCH). These sessions were designed to provide a confidential and supportive space for staff involved in the investigation to reflect on their experiences, ask questions, and access emotional support prior to their interviews. Meetings were held with the Chief Executives and senior representatives from both trusts to present the offer and discuss the proposed structure of the sessions. However, the sessions were not required due to their own local support frameworks.

Documentary Review

Workstream 2: Understanding all of the evidence.
Led by: IPSI Operations Manager, Nurture Health and Care Ltd.

The family expressed concerns that, during the previous investigation, not all available sources of evidence were fully explored. They believed that certain materials may have provided alternative or additional perspectives on the sequence of events.

In recognition of these concerns and to ensure a transparent and comprehensive approach, all clinical experts involved in this investigation have been asked to confirm the full scope of evidence considered during their reviews.

A broad range of documentary evidence was reviewed in support of this investigation. The family submitted an extensive collection of materials, including written correspondence, official letters, call logs, WhatsApp messages, videos, and photographs of Yusuf. In addition, clinical experts identified and reviewed further documentation relevant to their areas of analysis.

In response to a direct request from the family, the Family Liaison Lead and IPSI Chair facilitated a supported viewing of the CCTV footage from The Rotherham Hospital UECC department on 20 January 2025. This step was taken to enhance transparency and reinforce the family's engagement in the process.

Following the family viewing, the IPSI team conducted a detailed analysis of the CCTV footage to triangulate accounts and timelines. This examination helped to correlate visual evidence with documented assessment notes.

While Yusuf was in UECC for a considerable period, the CCTV footage viewed the time from 23.20/15.11.2022 when Mum and Yusuf walked into the Paediatric waiting room and take a seat, to 05.44/16.11.2022 when Mum and Yusuf leave the hospital. During this time the CCTV captures several staff interactions and the arrival and presence of Yusuf’s uncle. The interactions include times when Mum and Yusuf are seen with a member of staff in the medical corridor and accompanied by a member of staff into adjacent medical cubicles. At 01.23/16.11.2022 Mum, Yusuf and Uncle are escorted into a paediatric medical cubicle. Mum and Yusuf do not reappear from this cubicle until 05.35/16.11.2022. During this time members of staff are seen to visit the cubicle several times.

A full list of all evidential materials submitted and reviewed, and any items not used, with a clear rationale for their exclusion, is included in Appendix 3.

Information Gathering

Our investigation was built on a co-produced Terms of Reference designed to address questions together with an objective approach including triangulation of evidence.

This approach involves collecting and comparing data from multiple sources or methods to validate our findings. Our triangulation methodology encompassed the following:

- Review of relevant documents, including patient records, incident reports, and policy documents, enabling the understanding of the context, chronology and identify the facts in relation to Yusuf.
- We conducted structured interviews and 'conversations' and included the views of Yusuf's family. Additionally, we have documented the diverse perspectives on the incident, contributing factors, and potential improvements to systems.
- We undertook specific analysis of quantitative data from the healthcare system's databases to identify trends, patterns, and outliers related to the incident.

Our approach to the analysis included expert opinion, benchmarking current standards and a Structured Judgement Analysis, to consider the views of the organisations alongside the family's perspective.

The discoveries from this investigation have been synthesised into a thematic review, which enables the creation of safety bridging statements and recommendations to enhance patient safety and prevent the recurrence of similar incidents in the future.

Nurture's Safety Bridging Statement are a tool used within independent investigations or reviews to highlight a specific area of concern related to safety, without prescribing a fixed solution. Instead, it provides a clear, evidence-informed summary of the issue, allowing the receiving organisation the autonomy to develop its own safety action in response.

The purpose of a Safety Bridging Statement is to support the organisation in understanding the nature and potential impact of the concern, while empowering them to design a response that is specific, measurable, and proportionate to their own context, resources, and operational framework. It ensures that learning is transferred constructively, while respecting organisational accountability and the need for tailored safety improvements.

As part of factual accuracy, many organisations and the family commented on the influence of hindsight bias.

In the context of this investigation, we have been mindful of the role that hindsight bias can play when reviewing complex clinical events. Hindsight bias can lead to an overestimation of what could or should have been known at the time, often underestimating the pressures, uncertainties, and cognitive demands placed on staff, but should focus on the availability of clinical information which was available at that time. Professionals were operating in a dynamic environment where risk is constantly assessed and balanced.

However, organisational learning also requires reflection on how things might be done differently in future. Where learning has been generated using hindsight or retrospective insight, this will be made explicit. This ensures fairness to individuals while supporting improvements in system design, information flow, and team-based safety practices.

Investigative Approach

Investigation Element	Approach Taken	Application in the Investigation Context
Approach:	Inductive	Insights emerge from real-world experiences rather than testing predefined theories.
Philosophical Stance:	Critical Realism	Recognises objective standards (guidelines) but explores systemic and perceptual influences on decision-making.
Methodology:	Pragmatism	Aims to generate actionable improvements with psychological safety embedded.

Each expert report has been attached as an appendix together with the chronology. In addition, the CCTV chronology and a detailed chronology of the 20th to 21st November 2022 is included as an appendix along with other evidence and analysis.

Quality Assurance

Our analysis is embedded in the Patient Safety Strategy by following PSIRF principles and those of a Just Culture. Nurture also uses analytical tools to consider the perspectives of others to create organisational learning through a systems lens - The Four Types of Knowing.

These are explained below:

1. What are the key facts of the case?
2. What procedures have (or not) been followed?
3. What are the perspectives of others?
4. What is everyone's intuition telling them about this case?

The Four Types of Knowing are designed to identify key points, comply with procedures, gain a wider perspective, explore potential biases, and gain a sense of how the case feels to each group.

This investigation has attempted to move away from traditional investigation constructs, particularly in the view that an original investigation had been published but had created more questions, therefore the authors have taken the pragmatic decision to include their own perspective to help make sense of the complexity and misunderstandings.

This is often considered as moving away from the objectivity of a third-person detached analysis but has embraced the knowledge and skills of those involved in the analysis.

Our final reports are quality-assured through a final Quality Review process and approved by an additional senior team member to ensure that they have fully met the scope of the terms of reference and quality standards.

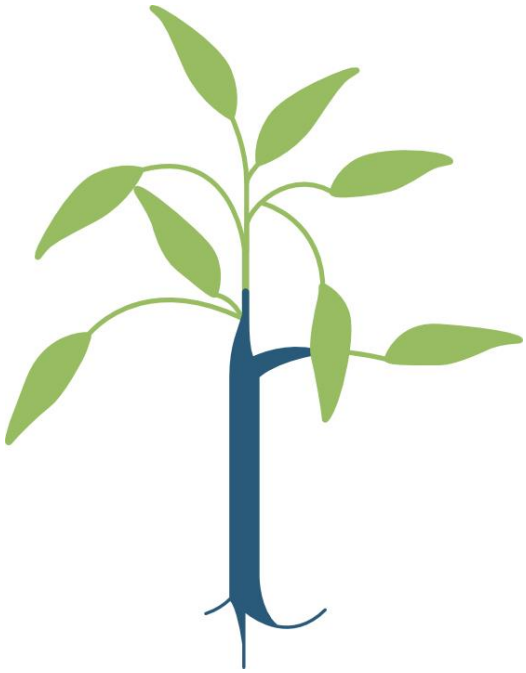
Chronology

This investigation examines the care and treatment provided to Yusuf across multiple healthcare settings. A detailed Chronology can be found in (Appendix 1), a summary of the key dates is identified below.

Summary Chronology

Date / Time	Event
13th November 2022	Yusuf had a high temperature and was generally feeling unwell
14th November 2022	In the evening of the 14th, Yusuf began complaining of a sore throat. Yusuf was unable to swallow solids and was only drinking sips of water.
15th November 2022 12.56	Visit to GP – oral antibiotics prescribed
15th November 2022 23.04	111 call
15th November 2022 23.30	Triage by ED
16th November 2022 05.44	Leaving ED – increased dose of antibiotics
18th November 2022 11.22	Visit to GP – additional oral antibiotics prescribed
18th November 2022 12.35	Family seek admission directly to ward
18th November 2022 13.00	999 call
18th November 2022 13.06	Ambulance arrived
18th November 2022 14.47	Presented to ED; triage completed, assessment and treatment commenced
18th November 2022 22.27	Transferred to The Ward
Night of 18th – 20th November 2022	Ward management by shared team: ENT and medical team
21st November 2022 Morning	It was identified that there was a possible deterioration overnight, which was acted on at 07.30am according to the clinical and nursing records and transferred to Paediatric Critical Care Unit later that day.
23rd November 2022 Morning	Resuscitation initiated; Yusuf died after a prolonged resuscitation

Findings



Findings

The investigation focused on the care and treatment received by Yusuf across multiple healthcare settings during the period between 15 November 2022 and 23 November 2022 (the date of Yusuf's death), during which he presented at different services on separate occasions.

This investigation has identified facts that are proven, highlighted where different accounts are present, separated out clinical judgement and included both the expert perspective and the family perspective to make sense of the complexity that is seen in the care of Yusuf.

In order to understand how clinical professionals make decisions, it is important to understand the decision-making process which is called clinical judgement.

Clinical Judgement

When assessing a patient, healthcare professionals follow a structured approach:

1. **Focused Assessment on Presenting Symptoms:**

The process begins by concentrating on the patient's current concerns. By asking questions about the presenting symptoms, we can direct our history-taking and examination to address the immediate issues effectively.

2. **Medical History:**

We gather comprehensive information, including past medical conditions, current medications, treatments, allergies, and other relevant details. This background helps us understand the patient's overall health context.

3. **Clinical Examination:**

A targeted physical examination is conducted, focusing on areas related to the presenting symptoms. This may lead us to recommend additional diagnostic tests, such as blood analyses or imaging studies, to further investigate potential concerns.

4. **Diagnosis:**

Combining information from the medical history, examination, and test results, we formulate a probable diagnosis. It's important to recognise that diagnoses are often based on what is most likely, considering the available evidence. Medicine involves uncertainties, and while we strive for accuracy, there is the possibility of error.

5. **Identifying Risks ("Red Flags"):**

In addition, we remain vigilant for signs that may indicate serious or urgent conditions, known as "red flags." Identifying these early is crucial for prompt intervention. However, assessing these risks also involves judgement and therefore there is an inherent possibility of missing an important clue.

6. **Evidence-Based Resources:**

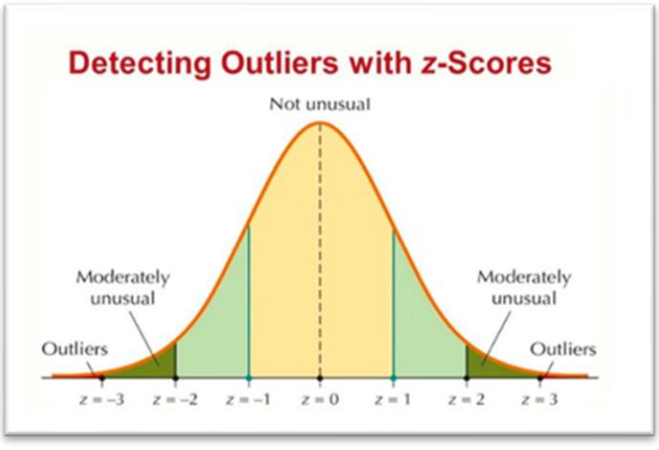
To support our clinical judgement, we utilise evidence-based guidelines, such as those provided by the National Institute for Health and Care Excellence (NICE) and the Royal College of Paediatrics and Child Health. These guidelines offer recommendations grounded in the latest research and expert consensus, aiding us in making informed decisions about tests, treatments, and care strategies.

Why Medical Assessments Sometimes Miss Atypical Conditions

Medical guidance and clinical decision-making are often based on what works for most people, the majority. These guidelines, developed from extensive research, evidence, and studies, represent what typically occurs in a large population. We can visualise this with a concept called the bell curve.

The middle of the curve (average) represents typical presentations—symptoms most people show.

The edges of the curve (outliers) represent unusual or atypical cases, where symptoms differ from the norm and are therefore harder to identify.



When healthcare professionals examine patients, they rely heavily on guidelines developed from the average cases. Most times, this works well. However, if you or your child is an outlier (on the edges of the curve), typical guidelines might not fit perfectly, making diagnosis more difficult.

Why did Yusuf die?

Much of the understanding by Yusuf's' family and the wider organisations has been with hindsight. Therefore, understanding how and why Yusuf died is a critical outcome of this investigation.

Without this information, we cannot fully understand how and why Yusuf died, or whether earlier intervention in his illness could have altered the outcome.

Yusuf's cause of death

The death certificate states the cause of death as;

1a) Type 1 respiratory failure

1b) Pneumonia

2) Tonsillitis

All these statements are factually 100% accurate. Yusuf did die of respiratory failure caused from pneumonia, where the blood could not get oxygen and was visualised in many ways including the X-rays seen after 21st November 2022.

He also had sepsis which is not on the death certificate but is described below.

The question however remains, what caused the pneumonia?

This is a critical question as the family believe that bacteria from the tonsils infected the blood stream (sepsis) and travelled to the lungs causing pneumonia, which led to Yusuf's death.

We note the letter dated 29th September 2023, from the Paediatric Consultant of Critical Care of SCH to Yusuf's Uncle includes the following statement:

I started by discussing Yusuf's cause of death agreed with the coroner stating he died from natural causes because of pneumonia (chest infection) and tonsilitis. I then showed 3 of Yusuf's chest x-rays demonstrating the progression of the lung disease (pneumonia). The initial x-ray on admission was near normal and the final x-ray showed complete "white out" of the right lung with worsening changes in the left lung. I explained that these changes were responsible for the low oxygen in his blood (hypoxaemia) and that extremely low blood oxygen levels were responsible for the cardiac arrest and failed resuscitation. [Yusuf's Uncle] *asked whether this course of events could have been picked up in Rotherham Hospital to which I answered no but earlier effective antibiotic treatment may have changed the course of the illness.* [Yusuf's Uncle] *also asked me to explain how tonsilitis could cause such pneumonia. I explained that although bacteria can spread directly form the tonsils to the lung it was more likely that the bacteria spread to the lung via the blood stream.*

The middle section of the letter refers to the care of Yusuf so has been omitted from this section and continues.

At [Yusuf's Uncle's] *request I explained the neck ultrasound performed on Yusuf was to rule out an illness (Lemiere's Disease)*[22] *that could involve the blood vessels in his neck. This ultrasound test showed no abnormalities. I also explained that Yusuf developed a leukemoid reaction which is an exaggerated white blood cell response to infection which causes his blood to be too thick. This reaction is well known but uncommon and was treated after much discussion by diluting his blood with fluid (hyperhydration). I explained that Yusuf his lung disease continued to get worse with low blood levels of oxygen (hypoxaemia) despite treatment with different life support machines. Yusuf's other organs (heart and kidneys) also started showing evidence of dysfunction. Yusuf needed medicine to support his blood pressure and may have later required kidney dialysis. Yusuf was being considered for a special treatment called ECMO where his blood would have been passed through an external oxygenator machine, but he had a cardiac arrest before this could be arranged. I explained that on the morning of 23rd of November 2022 Yusuf he had extremely low levels of oxygen in his blood which led to a cardiac arrest. The family unfortunately witnessed as he received CPR for 2 hours during which we got his heart started a number of times but sadly because his blood oxygen levels remained low, we were unable to keep his heart beating and save him.*

These excerpts from the letter to Yusuf's family confirmed their understanding of how Yusuf had died which was that bacteria from the tonsils infected the blood stream (sepsis) and travelled to the lungs causing pneumonia, which led to Yusuf's death.

The following email was written from Yusuf's Uncle on the 30th September 2023 to the Consultant in Critical Care asking some additional questions.

I have a few questions I would like to ask. If Yusuf did not have breathing issues and tonsillitis, Would have Yusuf Died anyway or could this have been prevented if Yusuf had been treated before when this infection started. What treatment could have stopped this infection when it was first picked up from getting soo bad that it's not been able to get controlled. He stopped eating, drinking, talking and had breathing issues, generally what should have been given to him when these symptoms come as Yusuf presented these at the start at GP and Rotherham. Could have an early indication stopped this for getting that bad that it's caused organ failures and no oxygen to his lungs? If it was treated at the start would he still have died or could the problem have been solved earlier.

[22] Lemierre's Syndrome is a rare but life-threatening complication of oropharyngeal infections (e.g., tonsillitis, pharyngitis, dental infections) caused by Fusobacterium necrophorum. It is characterised by septic thrombophlebitis of the internal jugular vein, leading to septic emboli that spread to the lungs and causes necrotising pneumonia. The ultrasound undertaken on 21st November did not show any thrombophlebitis and this cause was excluded.

The following response was written in response by the Consultant in Critical Care, on the 3rd October 2023.

Thank you for getting in touch and asking for clarification on these issues related to Yusuf's treatment. I will try my best to answer them. Many children catch tonsilitis and this is not usually preventable. The treatment for bacterial tonsilitis is antibiotics given by mouth. It appears that Yusuf was unable to take the antibiotics by mouth leading to a delay in effective treatment. Earlier intravenous antibiotics may have helped him fight the infection sooner and prevent complications. The question relating to his presentation at Rotherham are difficult for me to answer as I don't have the relevant information, but I expect the report of the investigation will address this question in detail. I am not sure I understand what you mean by "early indication stopping infection" but he developed a rapidly spreading pneumonia and sepsis (blood infection) which resulted in organ failure which could not have been predicted at the time of presentation. Earlier intravenous antibiotics may have helped prevent this from happening.

There was a further follow up letter from the Consultant in Critical Care following a 'Catch Up Bereavement Meeting' on the 10th October 2023.

Mr Ahmed asked if earlier intravenous antibiotics would have saved his life. I informed him that there is no way anyone can answer that question but on balance of probability, earlier effective antibiotic treatment could have helped changed the course of Yusuf's illness.

*We had further discussion surrounding Yusuf's cause of death. As the course of Yusuf's illness was unusual (including the leukemoid reaction) it is possible that he had an undiagnosed underlying condition as alluded to in the **** report. Had such an underlying cause been found I would have been included as 1C on the death certificate.*

A further question was written from Yusuf's family to the Consultant in Critical Care on the 18th October 2023.

*Thank you very much for your time and support. Apologies to bother you again, I just have a few questions following our last meeting. Having listened to our first meeting again and reading your summary sent on 6/10/2023, I understand that the leukemoid reaction was caused as a result of Yusuf fighting the already existing infections (tonsillitis leading to pneumonia). Reading your most recent summary of our meeting sent on 13/10/2023 has now left me feeling anxious regarding Yusuf's cause of death, because possibilities without any evidence can be endless and this has left me feeling confused. I would like to know on what basis is it being suggested that Yusuf had an underlying condition? Is it just because he was not presenting typical pneumonia? Yusuf was a perfectly healthy child prior to coming to hospital with no other symptoms or concerns that would have suggested a health problem, and neither was anything found. I would also like more clarity on the possibility of Yusuf having and also not having an underlying health condition. Without reference to the **** report and based on your experience and expertise when treating Yusuf, I would like to know that if there is a probability of Yusuf having an underlying*

condition, then is there also a probability that he did not have any underlying condition and that his death was caused by only by tonsillitis, pneumonia and respiratory failure as discussed in our first meeting.

This led to the reply by to the Consultant in Critical Care on the 18th October 2023.

*Thank you for contacting me seeking clarification relating Yusuf's illness. I'm sorry my last communication appears to have caused confusion. Without reference to the report Yusuf died as a result of very low oxygen in his blood because of pneumonia (chest infection). The leukemoid reaction complicates things a little but does not change Yusuf's cause of death. Major causes of leukemoid reactions include severe infections (like pneumonia), cancers, severe bleeding and pre-mature destruction of blood cells. The leukemoid reaction in Yusuf's case was caused by pneumonia but other causes needed to be investigated. The possible underlying illness I was referring to is leukaemia or other cancer as stated on page 29 of the **** report (see below) 3.69 As part of this investigation, Yusuf's blood results and his presentation were discussed with a paediatric haematologist in case this might have been an unrecognised and fast acting leukaemia or one of a range of other neoplastic processes. The haematologist felt it probably was not this. Unfortunately, we are unlikely to definitively ascertain why Yusuf died. The ***** investigators felt a post-mortem examination would have told us one way or another if he had leukemia or other cancer. This does not change the fact that Yusuf died from respiratory failure secondary to pneumonia. This situation is complicated but I hope this helps provide some clarity in this complex situation.*

All of the letters confirmed that the family believe that bacteria from the tonsils infected the blood stream (sepsis) and travelled to the lungs causing pneumonia, which led to Yusuf's death. The alternative explanations have not been part of the families understanding of how Yusuf died.

On interview with the Consultant in Critical Care (SCH) who has been the point of liaison for Yusuf and his family confirmed that he wrote the death certificate, and his view remained the same that the cause of death was tonsilitis, pneumonia and respiratory failure and that he felt therefore Yusuf did not need a post-mortem.

The Consultant in Critical Care completed a Medical Certificate of Cause of Death (MCCD). This form has different sections to help explain the medical reasons why the person died.

Part 1 – What directly caused the death
This section is used to show the chain of events that led to the death.

1a. This is the main cause of death and the final illness or condition that led directly to the person dying which was type 1 Respiratory Failure on the death certificate of Yusuf.

1b. This is the condition that led to 1a. It is the illness or problem that caused the main cause of death to happen which is recorded as Pneumonia.

Part 2 – Other conditions that contributed to the death
This section lists other important health problems the person had that didn't directly cause the death but may have made it more likely which was recorded as tonsillitis.

The Nurture Expert states:

Evidence of sepsis – rising CRP and white cell count, leukaemoid reaction which is likely to reflect a severe infection, in association with hypotension (>90ml/kg fluid bolus in 24 hours; need for two inotropic agents to support blood pressure), acute kidney injury and acute liver injury.

The chest and pneumonia is the likely source of sepsis. *This was complicated by wheeze and reactive airways disease.*

It is possible that the infection originated in the tonsils initially and spread. *It may also be possible that he had a viral infection in his upper respiratory tract (tonsils etc) which caused damage to the mucosal lining, and allowed entry of bacteria to the bloodstream. Secondary bacterial infections after a viral infection are well recognised with examples including Streptococcus pneumoniae, Haemophilus influenzae or Staphylococcus aureus bacteraemia/pneumonia after a wide variety of viruses (parainfluenza, adenovirus, influenza etc).*

Of note, no pathogens were found. The mycoplasma PCR was negative, as was an extended respiratory viral panel. Cultures taken were all negative (blood, urine, endotracheal secretions). Fungal markers were negative. A blood borne viral screen was negative (HIV and hepatitis).

A post mortem might have been more conclusive as deeper samples could be sent for microbiology. In addition, it is possible that Yusuf had an underlying genetic condition which resulted in him responding this way to an infection – tests for a primary immune deficiency might have provided an answer. Functional immune assays would have been difficult to interpret in a severely unwell child, but a sample could have been sent for genetic mutations associated with inborn errors of immunity (IEI).

The reason that an underlying cause is still being considered is due to the fact that death from pneumonia in high income countries is not seen frequently in children who are 5 years

old.[23] and usually samples would reveal an infective cause. It is therefore possible that another underlying cause has contributed which was undiagnosed.

Sheffield Children's Hospital provided a reflective statement which is available in Appendix 14.

Conclusion From All The Information Available

It is possible that the pneumonia developed either as a secondary bacterial infection subsequent to a viral infection in the throat/nasopharynx, which allowed bacteria to enter through damaged mucosal surfaces and then spread through the blood to the lungs and caused pneumonia and sepsis. They may not have the same pathogen causing the tonsillitis and the pneumonia and sepsis, but having a viral infection is a risk factor for a bacterial infection.

The complicating factor here is that no pathogen was found, so we cannot be conclusive either way.

Without more understanding of what caused the pneumonia, it is impossible to make a statement on whether IV antibiotics or earlier detection would have prevented Yusuf's death.

We understand that this is not the information that the family obtained initially and appreciate how this difference of professional opinion has led to confusion and emotional distress for the family.

It is noted that in the letter dated 29th September the Consultant in Critical Care (SCH) stated '*Mr Ahmed also asked me to explain how tonsilitis could cause such pneumonia. I explained that although bacteria can spread directly form the tonsils to the lung it was more likely that the bacteria spread to the lung via the blood stream'* and this was reconfirmed by the Consultant in Critical Care (SCH) on the 3rd October stated that '*The treatment for bacterial tonsilitis is antibiotics given by mouth. It appears that Yusuf was unable to take the antibiotics by mouth leading to a delay in effective treatment. Earlier intravenous antibiotics may have helped him fight the infection sooner and prevent complications. The question relating to his presentation at Rotherham are difficult for me to answer as I don't have the relevant information, but I expect the report of the investigation will address this question in detail.'*

The Consultant in Critical Care (SCH) further clarified on the 18th October: *Unfortunately, we are unlikely to definitively ascertain why Yusuf died. The **** investigators felt a post-*

[23] Overall, in 90% of the infection related deaths the child had an underlying health condition, including 68% who had a life-limiting condition (e.g., cerebral palsy), and 22% who had another underlying health condition (including prematurity). 10% had no underlying health condition. National Child Mortality Database (2023). Infection-related deaths in children and young people (2019-2022). NCMD Report.

mortem examination would have told us one way or another if he had leukaemia or other cancer. This does not change the fact that Yusuf died from respiratory failure secondary to pneumonia. This situation is complicated but I hope this helps provide some clarity in this complex situation.

Why Might Experienced Doctors Disagree on the Cause of Death?

Medicine often involves interpreting complex situations, especially when there are multiple medical conditions occurring simultaneously. Two equally experienced doctors might interpret the same evidence slightly differently. Sometimes infections occur at the same time but independently, while other times one infection may cause or worsen another. It can be difficult to tell exactly how these infections relate to each other such as whether an infection in the tonsils directly led to pneumonia, or whether they occurred separately. In addition, there remains the rarer possibility that there was another unknown diagnosis that created a worse outcome.

All clinicians, our Nurture experts and those at Sheffield Children's Hospital agreed that there was no causative agent was found.

The Consultant in Critical Care (SCH) has stated in their letter to the family on the 3rd October 2023: '*Earlier intravenous antibiotics may have helped him fight the infection sooner and prevent complications. The question relating to his presentation at Rotherham are difficult for me to answer as I don't have the relevant information, but I expect the report of the investigation will address this question in detail. I am not sure I understand what you mean by "early indication stopping infection" but he developed a rapidly spreading pneumonia and sepsis (blood infection) which resulted in organ failure which could not have been predicted at the time of presentation. Earlier intravenous antibiotics may have helped prevent this from happening.'* It is also important to include that the Consultant in Critical Care (SCH) did not have access to notes of any of the other organisations including TRFT.

Further clarification was sought from our Nurture Expert: Consultant Paediatric Emergency Medicine in relation to earlier administration of IV antibiotics at TRFT and they made the following statement: *I am clear that antibiotics at TRFT wouldn't have made a difference.*

Family Questions

Was there missed opportunities in identifying the severity of Yusuf's tonsillitis and preventing Yusuf subsequent death?

What was the cause of death of Yusuf?

Is the death certificate correct?

While tonsillitis is a common childhood illness, it is rarely a direct cause of fatal sepsis. The lack of a confirmed infectious agent in this case presents a diagnostic challenge and although it is possible that the infection originated in the tonsils initially and spread, this may not be the critical source of infection.

Pneumonia is the most likely source of sepsis and this was complicated by wheeze and 'reactive airways disease'. Reactive airways disease is the term for symptoms such as wheezing, coughing, and shortness of breath due to airway hyperresponsiveness. It is often used when a definitive diagnosis, such as asthma has not yet been formally diagnosed.

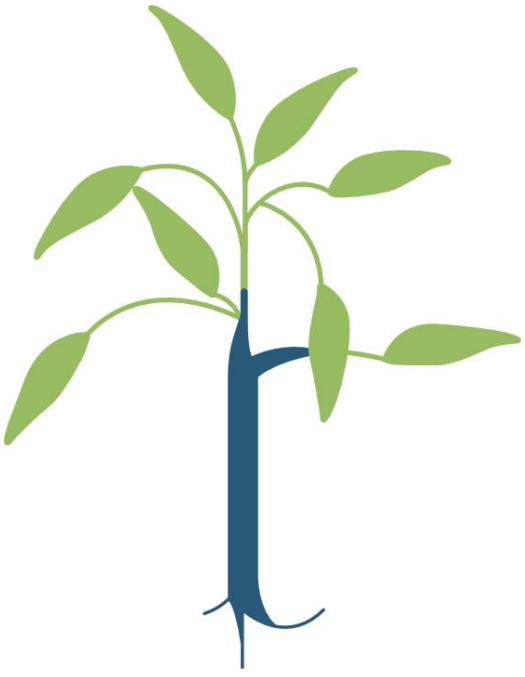
The diagnosis is therefore:

- Sepsis of unknown origin
- Pneumonia of unknown origin

A post-mortem would have enabled samples to be sent for microbiology. In addition, as Yusuf presented with symptoms that were not typical, it is possible that Yusuf had an underlying genetic condition which resulted in him responding this way to an infection. Tests for a primary immune deficiency might have provided an answer. Testing for an immune response would have been difficult to interpret in a severely unwell child, but a sample could have been sent for genetic mutations associated with inborn errors of immunity which may have been identified, and this would have enabled understanding if a contributing factor was missed.

Without understanding the aetiology and any sensitivity and resistance patterns of the pneumonia and sepsis, it is impossible to state whether treatments given earlier would have been effective or that any early intervention would have altered the subsequent death of Yusuf.

Review of Care Across Multiple Healthcare Settings



Review of Care Across Multiple Healthcare Settings

The review of care has drawn on a wide range of evidence to build a comprehensive understanding of the events that occurred. This includes a full review of the clinical records across all points of care, documentation and ‘WhatsApp communication’ related to the family's concerns and experiences, and a review of additional material to triangulate our findings.

Interviews were conducted with key members of staff to understand clinical reasoning and contextual factors. Alongside this, Structured Judgement Analysis (SJA) was applied at key decision points to consider the organisational perspective.

At the factual accuracy stage, there were discrepancies in the timeline of events, so an additional workstream was undertaken reviewing the circumstances between midnight and 09.00 on the 21st November 2022.

GP Surgery *(1st presentation)*

Review of the care and treatment received at the surgery

on 15 Nov 2022

1. GP Surgery: First Presentation

a. The Family Perspective

From the provided timeline:

Sunday 13th November 2022

• *Yusuf had a high temperature and was generally feeling unwell.*

Monday 14th November 2022

• *In the evening of the 14th, Yusuf began complaining of a sore throat. Yusuf was unable to swallow solids and was only drinking sips of water.*

b. The Medical Records

On the 15th November 2022 Yusuf presented to the GP, where he was seen by an advanced nurse practitioner. The medical record summary included the following: *Oral H: fever since weekend responds well to calpol c/o sore throat. Drinking well, reduced appetite, bowels an bladder as normal no cough. E: no rash raised bilateral cervical glands, ears NAD, throat red, inflamed, bilateral exudate present, airway clear, chest clear, no wheeze, no recession, no cough, hydrated. Plan: px as above bd for better concordance, push fluids and paracetamol. Review if fails to improve or any concerns. Signs of sepsis discuss, retention, non blanching rash, diff breathing to attend ed. Mum happy with plan.*

Observations included: Temp: 37.3 C, Capilliary Refill Time: 1 Seconds. Fever Pain Score 4

This meant that using clinical judgement, the practitioner identified that Yusuf was likely to have tonsillitis.

The standards for treatment are self-management and oral antibiotics[24].

Risks were considered which included pneumonia, with no signs of a cough and a clear chest, and no difficulties breathing described. Sepsis was also excluded.

Safety netting advice was given.

c. The Expert Opinion

The Nurture experts (Appendix 4*)* states: '*A fever pain score of 4 would be appropriate to treat with antibiotics and the BNFC does allow for a BD (twice daily) dose.*

[24] References

• National Institute for Health and Care Excellence (NICE) (2022). Sore throat (acute): antimicrobial prescribing. Available at: NICE website

• Royal College of Paediatrics and Child Health (RCPCH) (2023). Recognising and responding to critically unwell children. Available at: RCPCH website

Yusuf was unvaccinated; it's not clear if this was recognised in the consultation. Given the presenting symptoms, there was no specific cause for different interventions at this stage'

It was noted that pulse-oximetry, pulse and respiratory rate were not included however a focused physical examination should always include:

Ear, Note and Throat examination (typically visualisation of the throat, palpation of lymph nodes and visualisation of the tympanic membrane)

The conclusion of the Nurture experts (Appendix 4) was:
Yusuf presented with specific symptoms of tonsillitis of which the majority of cases are viral but the use of antibiotics is indicated (via National Institute for Health and Care Excellence; NICE) if utilising the FeverPAIN score. It is likely given the observations taken in the Emergency Department that he did not have significantly elevated heart rate or respiratory rate at presentation to the General Practice meaning escalation of care at this stage was not warranted. It is good practice, but not a national standard to support verbal safety netting advice with a written record (ideally in the language of the patient/family). Yusuf being unvaccinated probably should have warranted specific safety net advice but the management strategy itself at that stage would not have been different.'

d. Conclusion from all the information available

On the balance of probabilities, the presentation was likely to be tonsillitis and that appropriate consideration has been given to 'red flag symptoms' which were not present.

Yusuf's temperature was recorded at 37.3°C, and their FeverPAIN score was 4, meeting the National Institute for Health and Care Excellence (NICE) criteria for antibiotic use in suspected bacterial tonsillitis. As a result, the child was prescribed phenoxymethylpenicillin twice daily. Given that most cases of tonsillitis are viral and self-limiting, antibiotic treatment was an additional precaution, it was appropriate that Yusuf was recommended to be at home. Pulse oximetry, a non-invasive method to measure arterial oxygen saturation (SpO_2), is a valuable tool in assessing paediatric patients' respiratory status. Its routine use in primary care, however, varies and a study from 2011[25] revealed that only 20% of general practitioners reported using pulse oximetry to assess respiratory status, indicating that it is not yet a standard practice in many primary care environments. COVID has led to an increased adoption however it is unclear what the current uptake is.

The safety netting advice given was appropriate.

The family questions and response are answered further in the report.

[25] Plüddemann, A., Thompson, M., Heneghan, C. and Price, C.P., 2011. Pulse oximetry in primary care: primary care diagnostic technology update. British Journal of General Practice, 61(586), pp.358-359. Available at: https://doi.org/10.3399/bjgp11X572553 [Accessed 29 March 2025].

TRFT *(Emergency Dept)*

Review of the care and treatment received during attendance

15 Nov – 16 Nov 2022

2. TRFT: Emergency Department

a. <u>The Family Perspective of Clinical Care</u>

In the evening of the 15th November 2022 22:46

Yusuf' mum called 111, the telephone advisor conducted an assessment of Yusuf current physical health presentation over the last 12 hours. In the 111 call, Yusuf's mum described her concerns regarding how Yusuf's breathing had altered, he was taking in deep breaths and he was struggling to wake up and very lethargic all day. Yusuf's mum struggled throughout the assessment to answer the questions as Yusuf was sleeping and mum explained that it was difficult to answer the questions, due to his age and understanding. However, Yusuf did say his throat was painful. Yusuf's mum did say how she has noticed his breathing had changed, he is taking in deeper breaths and explained he is asthmatic, and she had never seen him do this before. After the advisor completed the assessment, he placed mum on hold and escalated the concern to the clinician on call, they stated Yusuf was 'CAT 3' and mum can make her own way to A&E, with Yusuf. The clinician agreed this was the best course of action for Yusuf to be seen, safety netting was given regarding taking a mobile phone, sitting Yusuf upright so it is more comfortable for him to breath and to take his inhalers with her, in case his symptoms got any worse. The advisor then reiterated this back to Yusuf's mum and the call ended.

Yusuf was taken to the TRFT ED by Yusuf's mum due to breathing difficulties as above.

Yusuf's mum kept the family informed of her continuing concerns and health care journey of Yusuf by WhatsApp messaging. This included the review of a family video.

In addition, the following was included in their bundle of evidence.

• *Whilst at the A&E department, Yusuf suffered from four episodes of severe breathing difficulty (see A&E CCTV footage).*

• *Yusuf was provided a bed in the A&E department for monitoring. In this time, only Yusuf's oxygen was monitored approximately 3 times throughout the night. His breathing episodes still continued and were not observed by staff throughout the night.*

• *Yusuf was seen by a doctor between 5 – 5:30am on Wednesday 16th November 2022. Upon examining Yusuf's tonsils, the doctor was extremely shocked, stating "that's horrible, the worst case of tonsillitis I have seen". He then went on to explain the severity of his tonsillitis. As the breathing episodes being experienced by Yusuf whilst he was in the waiting area were not observed by a nurse or doctor, Yusuf's mum described these to the doctor, to which the doctor reassured mum that this is normal and can take time to settle. The doctor was also informed of Yusuf not being able to eat or drink. The doctor prescribed another 5-day course of the same antibiotic but of lower strength, as he stated that the initial 5-day course alone was not sufficient. Yusuf was sent home.*

b. <u>The Medical Record – Full details are available in Appendix 15</u>

The following are excerpts from the medical record.

15th November 2022, 23.38:

Attended with mum – seen in GP today, diagnosed tonsillitis. Antibiotics had two doses.

Mum said he fell asleep and was breathing loudly, snoring and had never done that before. No LOC, No colour change.

Reduced diet, is drinking, has passed urine, had calpol

A: Patent

B: No distress

C: Well-perfused

D: Alert and orientated

E: Apyrexial, no rashes

Sepsis no suspected

RR: 22, O2 sats 99% on air, HR 99, Temp 36.8, Cap Refill <2 secs

POPs 0

Mild pain

Allocated waiting room (check list completed)

16th November 2022, 00.33

RR 22, O2 saturations 99% with nasal cannula, HR 108

00.52

Mum requesting to see Paediatric consultant gasping for breath.

Repeat observations – within safe limits.

Is apyrexial, No respiratory distress.

On observation, Yusuf is asleep and snoring.

Informed mum that we cannot get a doctor to see him at present.

Mum agitated, appears angry, shouting and asking for my name and that she will take this to the executive of the trust.

Apologies to mum regarding high capacity and waiting times. Reassurance given that nursing staff are monitoring son and will act accordingly. Mum has gone back to waiting room. Will give side room as soon as one becomes available.

01.36

RR 22, O2 saturations 98% on air, HR 88

01.37

Uncle of Yusuf came to nurses station and asked to speak to nurse in charge as he is not happy that Yusuf has not seen by medical team. ED Ward Manager spoken to uncle and updated him on situation in the department. Side room given to Yusuf. Continuous monitoring in situ. No respiratory distress observed. Yusuf nursed next to oxygen and suction. Mum aware of nurse buzzer.

01.49

No change

03.30

Yusuf clinically stable, with no respiratory distress, settled and sleeping between nursing interventions. No new concerns. No reports of pain or gasping episodes.

05.14

RR 22, O2 saturations 98% on air, HR 113 POPs 1

05.33

ED Clinician notes: Tonsillitis diagnosed today in GP started penicillin. Overnight snoring, no IWOB (increased work of breathing), eating little, drinking regularly small amounts. Fever. No rash, no head or neck pain.

Asthma: Monteleukast, Clenil and Salbutamol.

On Examination: asleep comfortable. SpO2 consistent, snoring. No features of respiratory distress. Chest clear (wider clinical assessment was normal – in detail in appendix 15) EWS 1, sepsis screen completed.

Throat – large red pustular tonsils and uvula.

Tonsillitis

Reassured regarding snoring, advice regarding respiratory distress and to return if worrying symptoms.

This meant that using clinical judgement, the doctor identified that Yusuf was likely to have tonsillitis.

The standards for treatment are self-management and oral antibiotics[26].

Risks were considered which included pneumonia, with no signs of a cough and a clear chest, and the snoring and sleep apnoea responsible for how Yusuf was presenting. Meningitis and sepsis was also excluded.

Safety netting advice was given.

c. Review of CCTV is recorded in Appendix 2

d. Organisational Perspective

The following was added to the report following factual accuracy checking:

- In response to episodes of 'choking', oxygen was monitored and from the move to the cubicle monitored continuously until discharge.
- Antibiotic prescription for penicillin as a strength of 125mg/5mls but to be given 250mg i.e. 10mls twice per day. Although the strength of the solution may have been 'lower' the dose intended to be given was the same. The course was extended to 10 days as this is the recommendation for treating tonsilitis with possible bacterial cause of streptococcus group A.
- The Trust was one of 14 field test sites who were testing proposed new urgent care standards intended to replace the 4-hour A&E target. During this period the Trust was therefore not working to the national 4-hour standard as we were field testing the new proposed metrics. This commenced 22nd May 2019, with a formal Memorandum of Understanding in place between the Trust and NHS England/NHS Improvement. Some of the rationale for the new metrics was to enable longer periods of review in Emergency Departments.

e. The Expert Opinion

The Nurture experts reviewed the evidence (Appendix 4) and included the following:

WhatsApp video with Mum reviewed by expert:

Yusuf sleeping on 15.11.23 at 22.22 *video link showed prior to arrival in the Emergency Department showing a child who is snoring with mild respiratory distress (it's subtle but there is some very slight suprasternal recession). Snoring in children is not uncommon, and not always pathological, however it can be a frightening experience for caregivers and*

[26] References

- National Institute for Health and Care Excellence (NICE) (2022). Sore throat (acute): antimicrobial prescribing. Available at: NICE website
- Royal College of Paediatrics and Child Health (RCPCH) (2023). Recognising and responding to critically unwell children. Available at: RCPCH website

there is a need to address what the cause of the snoring is and what the results of snoring may be.

SA: He keeps doing this every 5 mins

The experts further included: *His initial Paediatric Observation Priority Score (POPS) was 0. The PMH field in the initial notes entry report "Immunisations up to date". The reason for attendance is breathing difficulty and snoring (when he hadn't had this symptoms before) on the background of a recent diagnosis of Tonsillitis.*

He was not seen until 05:17 in the morning. Before this point he had observations at 23:30, 00:33, 01:36 and 05:14. All observations were within standard parameters i.e. no evidence of concern apart from the observations at 05:14 in which the heart rate was slightly elevated at 113.

There were interactions between the family and the staff at 00:24, 00:42 and 01:05 01:37. Following the discussion at 01:37 Yusuf was moved into a cubicle. These interactions related to concerns in regards to Yusuf's breathing, his retching and the delay in seeing a doctor.

The doctor who reviewed Yusuf recorded that Yusuf was eating little but was drinking small amounts regularly. The clinician felt the diagnosis was tonsillitis and extended the course of antibiotics. They document they reassured the caregivers regarding the snoring and document clear safety net advice.

He left the department at 05:35 and there is CCTV of walking out of the department holding his mother's hand.

The Nurture expert (Appendix 4) stated the following:

His time for assessment was within 15 minutes and given the pressures on the Emergency Department at that time (average wait was 225 minutes, with an average wait of 25 minutes for triage and 171 minutes from arrival to treatment) this can be seen as good practice.

It is reported by the GP that Yusuf was not immunised however the entry in the Emergency Department initial triage/assessment records says he was immunised. It's not clear whether the doctor who reviewed Yusuf validated this information.

The persistently low POPS is demonstration of a low acuity patient who didn't need further investigation and work up. In a study of over 24,000 children only a tiny proportion (0.06%) with an initial score of 0 returned and needed to be readmitted [Data available via Prof Roland].

There is debate regarding the potential severity of Yusuf's presumed dehydration. Not eating for even a couple of days in a child can be well tolerated if fluids are frequent and contain sugar. Noting this; best practice at the clinical review would have included a

documentation of Yusuf's urine output as this is a good proxy measure for hydration status. As long as the child is passing urine then poor feeding alone is not an independent risk factor. However, failing to address dehydration as a cause of concern further increases caregiver anxiety.

The wait to see a doctor was significant; however, waiting times for review were prolonged across the country at that point. A number of observations were taken at a frequency which was commensurate with the acuity that Yusuf had presented in (given his low initial score 4 hourly observations would have been acceptable practice).

Yusuf presented with clinical signs of tonsillitis but caregiver concern with breathing difficulty. There is nothing in the clinical record to support significant respiratory compromise requiring urgent intervention. It is reasonable to say that caregiver concern was not addressed however and staff responses to the caregivers' implicit anxiety perhaps exacerbated underlying concern rather than providing reassurance.

The experts answered the family's questions:

Is there any clinical evidence to suggest that Yusuf's earlier admission to TRFT for IV antibiotics, would have possibly prevented Yusuf's death?

I do not believe it would have done.

What was the length of stay in ED and whether this was a contributing factor to the death of Yusuf?

The length of stay was in excess of six hours, however observations were regular, reviews did occur and the final consultation was with the hindsight of a sequence of normal observations supporting the decision to discharge.

The Trust however were not working to these standards as they were participating in a national pilot.

f. Conclusion from all the information available

On the balance of probabilities, the presentation was likely to be tonsillitis and that appropriate consideration was given to 'red flag symptoms' which were not present.

Yusuf did not have a temperature, their Paediatric Observation Priority Score (POPS), which is a method of combining vital signs (breathing rate and heart rate for example) into a single measure which helps assess how unwell a child is, was 0 or 1 (heart rate 113) and he showed no evidence of respiratory distress with normal oxygen saturations throughout the visit.

He did show symptoms of snoring or noisy breathing, which can occur in young children with enlarged or inflamed tonsils due to tonsillitis. Enlarged tonsils can temporarily block

or narrow the airway during sleep, causing snoring, noisy breathing, and occasionally short pauses in breathing (apnoea). While this can appear worrying, it is an observed issue and acted as further evidence that Yusuf was experiencing tonsillitis.

Snoring and Sleep apnoea (obstructive sleep apnoea, OSA) affects approximately 1–5% of children, with peak prevalence between ages 2 to 6 years due to enlarged tonsils and adenoids[27].

One other risk which would have influenced decision making which is not apparent in the notes but was discussed at the structured judgement review was the risk of admission.

Hospital admission for a child carries certain risks, particularly concerning hospital-acquired infections (HAIs). Although not explicitly stated in the medical records, this would form part of the risk assessment and although the notes identify Yusuf as not vaccinated, risk of admission form part of the decision-making process.

With the benefit of hindsight, unvaccinated children may face heightened vulnerability to infections such as COVID-19 during hospitalisation. A study published in 2023 highlighted that infants under six months, who are ineligible for COVID-19 vaccination, exhibited the highest COVID-19 hospitalisation rates among paediatric groups[28]. This underscores the increased risk unvaccinated children may face regarding Hospital Acquired Infections like COVID-19 or other infections.

The COVID-19 pandemic has also impacted the epidemiology of other respiratory viruses and remains poorly understood.

The safety netting advice given was appropriate.

g. Triangulation against witness statements

Yusuf's mother and uncle have expressed their dissatisfaction with the interactions and demeanour of the nursing staff in the UECC on the night of November 15, 2022. They described the nurses as being rude and neglectful of both Yusuf's and his mother's needs.

Both family members requested that we review the CCTV footage, which was completed on two separate occasions. However, it is important to note that CCTV has its limitations; it lacks audio, and while we can observe some interactions between the staff, Yusuf's mother and his uncle we cannot draw definitive conclusions regarding the nature of these interactions.

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[27] Kaditis, A. G., Alvarez, M. L. A., BoudewYusufs, A., Abel, F., Alexopoulos, E. I., Ersu, R., ... & Verhulst, S. (2016).
Obstructive sleep-disordered breathing in 2- to 18-year-old children: Diagnosis and management.
European Respiratory Journal, 47(1), 69–94.

[28] Centers for Disease Control and Prevention (CDC), 2024. Protecting infants and children from COVID-19-associated hospitalization. [online] Available at: https://www.cdc.gov/ncird/whats-new/protecting-infants-and-children-from-covid-19-associated-hospitalization.html

We met with three members of the nursing team to gather their accounts of the evening. Their perspective contrasts with that of the family; they contend that, although they were busy, they attended to Yusuf's needs appropriately and in accordance with best practices. Our review of the CCTV footage aligned with the entries in Yusuf's medical records.

One member of the team was surprised by the family's allegations, as she believed she had established a positive rapport with Yusuf's mother. This was agreed by Yusuf's mother, that their interaction had been positive.

The family requested that we speak with a member of the public, referred to here as J, who they believed could support their viewpoint on the nursing staff. J was present in the waiting area during the incident and observed Yusuf becoming distressed due to breathing difficulties. J approached the nurses' station and asked a nurse to assist Yusuf, stating she responded by saying that Yusuf's mother should come find her if she needed help. J described the nurse's demeanour as rude.

We addressed this account with the nurse involved, who acknowledged that J approached her at the nurses' station but insisted that her actual response was that if Yusuf's mother wished to see her, she knew where to find her. The nurse denies being rude in any way.

Perceptions of interactions can vary greatly, and it is widely recognised that family members may be particularly sensitive in stressful situations. In such contexts, nurses who are under pressure might respond in a manner that could be perceived as transactional, potentially coming across as rude or indifferent.

In conclusion, we are unable to form a definitive opinion, as the evidence at our disposal remains inconclusive. However, we felt it was essential to include the differing perceptions in our report, as they reflect the honestly held beliefs of all parties involved.

h. Staffing Levels and Skill Mix: Full report can be seen in Appendix 7

i. Family Questions

1. What were the staffing levels of the Emergency Department and the Paediatric ward at the time Yusuf was being assessed. This includes the what skill mix was present, ie what band or grade of staff were on duty and has there been any improvement in the ratio of appropriately trained staff in response to the initial report recommendations.

Emergency Department.

From the Nurture expert report in Appendix 7.

On the night duty there were nine Registered Nurses on duty, two Band 6 and seven Band 5. Five of the Band 5 nurses were agency staff, covering paediatric and adult emergencies.

On 15 November 2022, the Emergency Department rota showed a total of 5 consultant shifts, of which 1 was vacant, leaving 4 covered which included overnight. Middle grade doctors were scheduled for 9 shifts, all of which were fully staffed. Junior doctors were allocated 15 shifts, with 2 left unfilled, resulting in 13 staffed shifts.

We have not reviewed any recent rotas and this is available through the action plan completion by each organisation.

2. What was the bed occupancy of the paediatric ward at the time Yusuf was being assessed.

This has not been formally assessed but we have had confirmation in an interview that there were two beds available on the paediatric ward.

3. What was the length of stay in ED prior to being admitted and whether this was a contributing factor to the situation.

His time for assessment (triage) was within 15 minutes and given the pressures on the Emergency Department at that time (average wait was 225 minutes, with an average wait of 25 minutes for triage and 171 minutes from arrival to treatment) this can be seen as good practice. It was exceptionally busy with over 100 people in the department when Yusuf arrived.

It is noted that the NHS England Operational Standard did not apply and TRFT was one of 14 field test sites who were testing proposed new urgent care standards intended to replace the 4-hour A&E target. Paediatric standards (RCPCH)[29] suggest that critically unwell children should be reviewed by a senior clinician within an hour.

Yusuf did not meet the criteria for being critically unwell so therefore did not require seeing in 1 hour.

The extended wait (over 6 hours) is above best practice benchmarks, even in a resource-constrained system albeit the pilot as described is noted.

However, the observations were stable, and the overall clinical impression was of low acuity.

Length of stay alone was unlikely to have been a direct cause of deterioration and could also be considered as an extended period of observation so not a contributing factor to Yusuf death and was seen by the hospital staff, albeit not medical.

[29] https://www.rcpch.ac.uk/resources/all-resources

4 Would earlier administration of IV antibiotics possibly prevented Yusuf's death.

From the Nurture expert report in Appendix 4*: Is there any clinical evidence to suggest that YN's earlier admission to TRFT for IV antibiotics, would have possibly prevented YN's death? I do not believe it would have done.*

This was further clarified subsequently in the Factual Accuracy check and confirmed that there was no requirement for IV antibiotics at TRFT.

GP Surgery *(2nd presentation)*

Review of the care and treatment received at the surgery

18 Nov 2022

3. GP Surgery: Second Presentation

a. **The Family Perspective**:

According to the Family Evidence Bundle the following was stated:

Friday 18th November 2022 • After no improvement, and no food/little drink being consumed, Yusuf's mum made another appointment with the GP. • Yusuf was seen by the GP at approximately 11:30am. The GP checked Yusuf's tongue/tonsils, and listened to his chest. He explained Yusuf has severe tonsillitis and needs IV antibiotics. He insisted that Yusuf should be taken to the A&E department by the evening if there is no improvement in his condition. Yusuf's mum requested to be referred to the children's ward at RGH, but was told by the GP that they are unable to do that, and she needs to go to the A&E department. Yusuf's mum then insisted to the GP that if he knows Yusuf needs IV, then why can he not be referred. The GP persisted that they would need to go to A&E. Yusuf's mum then asked how long she should wait until taking him the A&E, to which the doctor responded, "By the evening, I wouldn't wait any longer than that". No respiratory assessment conducted (i.e., oximeter).

Yusuf's Mum kept the family informed of her continuing concerns and health care journey of Yusuf by WhatsApp messaging.

b. **The Medical Record**

18th November 2022, 08.37 History: spoke to mum, 4 days of PenV started for tonsillitis, states still feels no better, not eating much drinking fluids, known asthma , not wheezy or SOB, was seen in OOH on tues adv 10 days of PenV, Plan: f2f booke for exam.

11.22: History: F2F

Went to A&E on PenV for further 5 days to make 10 day course, on day 3 now, started with cough since yesterday on paracetamol, eating less but drinking and wetting nappies,

Examination: O/E - temperature elevated 39.3 O/E - pulse rate 122 bpm Cx LN Throat:enlarged tonsils with exudate, chest clear no recession.

Plan: adv PO fluids, paracetamol, continue Pen V, start erythromycin, worsening symptoms red flags advised safety netted,

Adv if no improvement , to attend A&E

Erythromycin ethyl succinate 250mg/5ml oral suspension - 100 ml - 1x5ml spoon 4 times/day prescribed.

c. The Expert Opinion

The Nurture expert's report found in Appendix 4 state: *Yusuf is documented has having a temperature (39.3C) a heart rate of 122 and no significant work of breathing. A respiratory rate was not recorded and neither were oxygen saturations. The GP felt Yusuf still had severe tonsillitis and altered the antibiotics to erythromycin (250mg/QDS).*

Safety net information was included but how this was perceived by the family differs.

d. Triangulation against witness statements

This was further supported by an interview and a structured judgement review and included the confirmation that the GP advised if no improvement to take to A&E as he might need IV antibiotics and that the GP added the antibiotic to erythromycin (250mg/QDS) as an adjunct so was on Penicillin and Erythromycin.

e. Conclusion from all the information available

On the balance of probabilities, the presentation was likely to be tonsillitis and that appropriate consideration was given to 'red flag symptoms' which were not present.

The standards for treatment are self-management and oral antibiotics which were extended as he was still not improving[30].

Risks were considered which included pneumonia, but had a clear chest, although was now presenting with a cough.

Safety netting advice was given. Based on the available GP assessment data and expert opinion, this was an elevated temperature of 39.3°C, pulse rate of 122 bpm, enlarged cervical lymph nodes, and enlarged tonsils with exudate, the child's clinical condition would likely generate a mildly elevated Paediatric Early Warning Score (PEWS) or Paediatric Observation Priority Score (POPS). The absence of respiratory distress (clear chest, no recession) excludes a critically unwell presentation. However, to calculate a definitive PEWS or POPS, additional parameters such as respiratory rate, oxygen saturation, responsiveness, and perfusion would typically be required.

The medical history from the GP record did not include any reference to breathing, but mum references the ongoing sleep interruptions in the WhatsApp, which have not led to reassurance. Pulse Oximetry was discussed on page 51.

[30] National Institute for Health and Care Excellence (NICE) (2018). Sore throat (acute): antimicrobial prescribing (Guideline NG84). Available at: https://www.nice.org.uk/guidance/ng84/resources/sore-throat-acute-antimicrobial-prescribing-pdf-1837694694085 [Accessed 29 March 2025].

f. Family Questions

Three questions have been posed from the General Practice

The experts have reported on these questions from their report which is available in Appendix 4

1. Why was there no pulse oximeter?

At that period of time, both the nurse and the doctor, completed a focused examination for tonsillitis and were not routinely using a pulse oximeter. It was available but they did not feel it was necessary for their assessment as they were not concerned about oxygen saturations.

A full respiratory assessment including pulse-oximetry is now undertaken as part of routine assessment of all ill children.

2. Was the GP able to refer directly to Rotherham Hospital paediatric ward?

The GP stated that it was inappropriate to directly refer acutely unwell children to the paediatric ward and that they must go to emergency department for stabilisation and to commence treatment and admit appropriately.

The Nurture Expert included *'It is not clear exactly what was said regarding the option of direct access to the ward but this would not be standard national practice (especially if the child had not been an inpatient recently) and therefore return to the Emergency Department is not an unreasonable course of action if immediate referral wasn't felt to be necessary.'*

3. Did the primary care service respond in line with national guidance in relation to their growing concerns for Yusuf health.

The Nurture Expert included *'It is likely that at that time he did not have specific red flag features warranting urgent intervention however the treatment decisions are not likely to have resulted in clinical improvement and it is likely that the caregivers underlying concerns have not been addressed'.*

The Family

Review of the family trying to access admission

4. The Family Trying to Access Admission

a. <u>The Family Perspective</u>: (From the family bundle evidence)

Yusuf was seen by the GP at approximately 11:30am. The GP checked Yusuf's tongue/tonsils and listened to his chest. He explained Yusuf has severe tonsillitis and needs IV antibiotics. He insisted that Yusuf should be taken to the A&E department by the evening if there is no improvement in his condition. Yusuf's mum requested to be referred to the children's ward at RGH, but was told by the GP that they are unable to do that, and she needs to go to the A&E department. Yusuf's mum then insisted to the GP that if he knows Yusuf needs IV, then why can he not be referred. The GP persisted that they would need to go to A&E. Yusuf's mum then asked how long she should wait until taking him the A&E, to which the doctor responded, "By the evening, I wouldn't wait any longer than that". No respiratory assessment conducted (i.e., oximeter).

This continued to a telephone conversation with the hospital children's ward where Yusuf's uncle begs the ward to take Yusuf as he was not able to breathe. This was declined and the family ring 999. The family recall being told, "We don't have any beds or doctors available, I can't just get a bed out of the air."

Yusuf's Mum kept the family informed of her continuing concerns and health care journey of Yusuf by WhatsApp messaging. Family photograph reviewed.

Ambulance Service

b. <u>The Family Perspective</u>: (From the family bundle evidence)

999 call on the 18th November 2022.

Yusuf's mum gives a clear summary of Yusuf's condition stating "the GP stated he will need IV drip" if he's not getting better. He was sucking in his belly as he is breathing and concerned that Yusuf is struggling to wake up. He wouldn't open his eyes and was just fidgeting. He was breathing harder every few minutes. Regarding his asthma, it has been bad in the past but he had not shown these symptoms before and his asthma had been fine recently.

The clinician stays on the phone till crew arrive and are patient facing. The operator escalated the call due to his alertness, age (5yr) and after given the summary of his tummy sucking in breathing.

The paramedics arrived at 13.04 on the 18th November.

From the family evidence bundle the following was stated:

Carried out the observations, and put Yusuf on oxygen immediately as he was struggling to breathe. The paramedics planned to take Yusuf to RGH. Mum requested for Yusuf to

be taken to Sheffield Children's Hospital (SCH). The paramedics refused, and said "we are not a taxi service". Yusuf's mum called Z [Yusuf's Uncle] to inform him of this. Z [Yusuf's Uncle] spoke to the paramedics on the phone loudspeaker and demanded for Yusuf to be taken to SCH. The paramedics once again repeated that they are not a taxi service and can only take patients to the closest hospital. They also suggested "you can take him yourself, but he needs oxygen". • Z [Yusuf's Uncle] then called 999 to ask about his rights, as he did not want to ask beyond what he can. He explained the conversation he had with the paramedics, and was told by the 999 operators that the paramedics must take them to their (patient's) chosen hospital or arrange a means of getting there for them. After Z [Yusuf's Uncle] explained the 999 call to the paramedics, the paramedics then took Yusuf and Mum to the SCH, to the A&E department.

18th November 2022 14.05 – 14.30

Yusuf's Mum kept the family informed of her continuing concerns and about the health care journey of Yusuf by WhatsApp messaging.

c. <u>The Medical Record</u>

CAD Call: 18th November 2022 12.59

On Scene: 13.04

Primary Assessment: 13.21

Left Scene: 14.00

At Destination: 14.34

Handover: 14.54

ACVPU: Alert Initial Acuity: Low Acuity Level Emergency Care

Airway: ClearBreathing: Normal Circulation: Radial Pulse C-Spine: Clear

Catastrophic Haemorrhage: No

Presenting Complaint: Throat-sore

History of Presenting Complaint: Patient has been unwell since Saturday with a temperature. Sunday morning patient was still unwell, Monday evening Mum says patient was complaining of a sore throat. Mum booked patient in to see their GP and was diagnosed with tonsillitis and was given a course of antibiotics for 5 days. Tuesday night mum took patient to ED as patient was waking up jumping. Patient was given another 5 days of antibiotics after being told patient did not have enough and carry on taking the full amount. Today mum states that he has seen his GP again after deteriorating and was given more antibiotics ?chest infection. Patient on day 4 of antibiotics rang 999.

On arrival: Patient on sofa lethargic GCS15

A: Clear B: Equal Rise and Fall of Chest, No DIB, NO SOB, Cough since yesterday given antibiotics today C: Skin pale, no cyanosis D: Temperature 38.5 BM 8.1 E: No other illness or injury known at this time. Pt [Yusuf] was diagnosed with tonsillitis on Tuesday by his GP and given a course of antibiotics for 5/7 days. Mum states pt [Yusuf] has been taking the antibiotics and is still not getting any better. Mum also says she has been back to the GP today and the GP states the patient has a chest infection and has been given more antibiotics for another 5/7 days. Mum also states that the GP has told her if pt [Yusuf] is still unwell PM to take pt [Yusuf] to ED for IV antibiotics. Pt [Yusuf] not able to eat and drink properly. Mum states that pt used toilet this morning for a wee. Last opened bowels two days ago.

From the electronic patient record: the ePR records observations taken at 13.18hrs and these are captured twice within the documentation. Both show Yusuf oxygen saturations were recorded at 91%. The observations taken at 14.15 highlight oxygen saturations to be at 99%.

This is the relevant exert from the medical record. Further information is available on the communication about which hospital to take Yusuf and is included in Appendix 4 and Appendix 6.

d. <u>The Expert Opinion</u>

The Nurture Expert Paramedic report is available in Appendix 6 and Appendix 4 from the Medical Experts.

The ambulance crew arrived at 13:04 (within national response time of 8 minutes). The initial observations included a Temperature of 38.5C, Heart Rate 160, Respiratory Rate 32 and Oxygen Saturations of 91%. He was given oxygen (2L) which was documented as dropping when his oxygen mask was removed.

His Capillary refill time does not appear to have been documented and this is relevant as concerns regarding his level of alertness and tachycardia could mean he was in shock. His arrival observations in Sheffield are not consistent with clinical shock however.

It's stated the diagnosis is tonsillitis but this is inconsistent with the presenting sign of low saturations.

The ambulance crew arrived to a child who had an oxygen requirement and a febrile tachycardia. The appropriate response is to convey this child to a secondary care facility which they did.

e. Conclusion from all the information available

On the balance of probabilities, the presentation was no longer only tonsillitis as the 'red flag symptoms' were present for the first time on a clinical assessment.

Yusuf required transfer to the nearest Emergency Department (ED) to enable an assessment of his low oxygen saturations together with his presentation of a temperature, high heart rate and respiratory rate. JRCALC guidance states that paediatric oxygen saturation should be maintained at 95% or above.

In addition, to the requirement for an urgent assessment, consideration of continuity of care would also form part of the decision making. The nearest ED was the hospital that had previously treated Yusuf.

The ambulance crew appropriately administered oxygen when Yusuf's saturation fell to 91% and noted that when oxygen was removed, the saturations dropped again so oxygen was continued.

The difference of opinion and how this was considered is examined in detail in Appendix 6, as the beliefs of the family about the Emergency Department of the nearest hospital meant they no longer trusted this service and considered there may not be doctors or beds available for Yusuf.

f. Family Questions

1. Did the ambulance service respond in line with national guidance in relation to their growing concerns for Yusuf's health, which included specifically considering Yusuf's oxygen saturations.

The JRCALC identifies within the chapter of Medical Emergencies in Children – Ensuring adequate Oxygenation section. That:

a. *adequate oxygenation is essential to all very sick children; administer high concentration oxygen (O2) (refer to oxygen protocol for administration and information) via a non-re-breathing mask, using the stoma in laryngectomee and other neck breathing patients to maintain an oxygen saturation of 95%*
b. *high concentration O2 should be administered routinely, whatever the oxygen saturation, in children with sickle cell disease or a history of cardiac disease*
c. *if the child is distressed by the presence of a mask, ask the parent to help by holding the mask as close to the face as possible. If this still produces distress, wafting O2 across the face directly from the tubing (with the facemask detached from the tubing) is better than nothing*

The JRCALC Guidance is clear that Oxygen saturation levels for a child should be maintained at 95% or above.

The guidelines advise that any concentration of oxygen levels in a child below 95% the child should be considered hypoxic (Hypoxia means 'caused by not enough oxygen being available to the blood and body tissues').

The patient care record completed at the time of the Ambulance crew attendance to Yusuf. Yusuf is identified by having:

- *18/11/22 13:18 hrs Oxygen level at 91%*
- *18/11/22 14:15 hrs Oxygen level at 99%*

This would indicate that Yusuf required supplementary oxygen to assist his breathing.

It would be appropriate for the Ambulance crew to have placed a paediatric oxygen mask over Yusuf's face and to supply him supplemental oxygen for the time Yusuf was in the care of the Ambulance crew.

The supplementary oxygen support to Yusuf's breathing should have been undertaken in line with having a paediatric pulse oximeter attached to one of Yusuf's fingers.

- *A pulse oximeter measures your blood oxygen levels and pulse*
- *Here is a clear guide to support understanding on the use of pulse oximeters, please note the guidance is directed towards adults, as such does not identify the points I raise below. pulse-oximeter-easy-read-2022-digital.pdf*
- *Not using the right size oximeter can affect reading, such as using an adult probe on a small child*
- *There is clear research that some skin tones can also cause problems with getting a clear reading*
- *It is unclear from the basic evidence provided on the patient care record if any of the above we considered and actioned*
- *There was an NHS alert issued by NHS England and Improvement in December 2018 identifying Risk of harm from inappropriate placement of pulse oximeter probes: Patient_Safety_Alert_-_Placement_of_oximetry_probes_FINAL.pdf*

It is clear to me from the evidence provided and the statement on the patient care record that Yusuf required supplementary oxygen support while in the care of the Ambulance crew.

2. Why there was a delay in him being admitted to Sheffield Children's hospital, despite being informed that Yusuf was on 'high alert'.

Expert 1: There was a challenge from the uncle (who wasn't present) in taking Yusuf to Sheffield rather than Rotherham. Given the clinical information available to the ambulance crew at that time it would not have been inappropriate to take Yusuf to Rotherham. The

decision not to take him to Rotherham, or any delays relating to conversations around his disposition, I do not think altered the eventual outcome.

Expert 2: It seems proportionate from the evidence that the Ambulance crew consider removal to the nearest local Emergency Department, given the evidence of Yusuf's ability to sustain his oxygen levels and the need for Yusuf to re assessed by a Doctor.

Ambulance crews are required to provide emergency care to maintain, save or sustain life.

Their key aim is to ensure that a patient is transported to the nearest available care facility to support the patient medical needs.

The NHS charter is clear that all users of NHS services have a right to choose the location they receive treatment.

Ambulance service work can conflict with this principle on some occasions. This is due to the nature of the medical emergency the patient is experiencing.

As Ambulance crews have limited drugs and equipment in comparison to the Nurses and Doctors equipment within an Emergency Department, the Ambulance crew are required to:

- *Rapidly evaluate the medical needs of the patient*
- *Take action to support, save or sustain life*
- *Transport to the nearest available Emergency Department for further care*

Some hospitals will provide specialist focus care such as Children's Hospitals, Trauma Hospitals etc. the ambulance crew are required to consider this as part of their evaluation of the situation, their risk assessment of the harm to the patient if any journey time is extended (where another Emergency Department may be closer to support lifesaving treatment).

I do not believe it was necessary for the situation to escalate into a difficult conversation.

3. Did the difference of opinion in relation to Yusuf attending Rotherham or Sheffield contribute to the delay in Yusuf's care.

There is no evidence provided that the delay in the ambulance crew transporting Yusuf to Sheffield Hospital had any impact on his outcome which is agreed by all experts.

The behaviour and attitude of the crew did not support the required standard expected of NHS staff, NHS Constitution and conduct. This is discussed further in Appendix 6.

I further believe the behaviour of the crew had a significant impact of the patient and family experience, in what was clearly already a very stressful situation.

SCH

Review of the care and treatment received during admission

18 Nov – 23 Nov 2022

5. SCH: Emergency Department

a. The Family Perspective

From the family bundle of evidence:

Upon arriving at SCH, Yusuf was immediately given a bed in the A&E and was observed by a doctor. Soon after, Yusuf was seen by several doctors, whom all stated that Yusuf has severe tonsillitis. All doctors having examined Yusuf were surprised regarding the severity of the condition of his tonsils.

• Yusuf was given medication, and over the next few hours he was consistently observed by doctors and nurses. In this time, he also had a chest x-ray. The doctor explained the results of the x-ray to mum, outlining that he has a small infection on his chest.

• Whilst in the A&E department, a doctor apologised to Yusuf's mum for double dosing Yusuf with a medication/steroid that is used for airways and wheeziness. The doctor explained that a possible effect of this could be high blood sugar, so they began monitoring Yusuf's blood sugars.

• At approximately 10pm Yusuf was taken into The Ward.

Yusuf's Mum kept the family informed of her continuing concerns and health care journey of Yusuf by WhatsApp messaging.

b. The Medical Record

This has been summarised by the experts as the medical record is paper-based and in multiple documents.

The Nurture medical expert reports are available in Appendix 4 and the Nurture expert nurse review in Appendix 5.

Yusuf arrived at 14.34 with handover at 14.48. A verbal handover between the ambulance crew and the triage nurse, takes place and then the electronic entry is made once the child is booked in at reception. The first nursing record was at 14.48 by a triage nurse. With an additional record at 15.13 and regular nursing and medical entries with the last entry being 22.15 before being admitted to The Ward.

Yusuf was brought in by ambulance and assessed by an emergency department doctor at 15.13, clerked for admission by a ward based paediatric SHO at 16.40, reviewed by the ward based paediatric registrar at 18.50 (and discussed with the paediatric Consultant on call, and the diabetes specialist consultant over the phone at this point) and seen by the ENT registrar at 21.00 (although there is a note with a verbal plan at 20.25).

Bronchodilator therapy was given at 15.10 (salbutamol 10 puff x 3). He received a dose of Dexamethasone (0.6mg/kg) at 15.50pm in ED.

The team noted that he looked unwell, but not septic, and the assessment included concerns regarding both upper airway obstruction due to tonsillitis, as well as wheeze and difficulty breathing associated with a lower respiratory tract infection. He was managed accordingly with bronchodilator therapy, corticosteroids (Dexamethasone at an asthma dose 0.6mg/kg) and IV antibiotics (Penicillin initially, with metronidazole added following discussion with the ENT team). A blood gas was performed at 18.34 which showed a normal pH and base excess, potassium of 2.69, glucose of 16.7 and lactate of 2.58. The blood glucose of 16.7 was felt to be a stress response, with a plan made to monitor to rule out diabetic ketoacidosis following discussion with the on call diabetic consultant. The raised lactate and low potassium were likely related to back to back salbutamol treatment - a plan was made for a repeat gas to confirm resolution. Lab bloods showed a raised white cell count of 16, with neutrophils of 14, but a reassuring CRP of 40. In addition his platelet count was 99, although this was not commented on. The registrar noted at 18.50 that the chest x-ray in ED was 'NAD'.

The X-ray report reported on 19th November 2022 - *Normal cardiomediastinal contour. There is marked perihilar bronchial wall thickening that extends peripherally into all zones but particularly the lower zones. Appearances in the left lower lobe are suggestive of some focal peribronchial infiltrates/peribronchial air space change. No pleural effusion or pneumothorax.*

Overall appearances would be in keeping with lower airways inflammatory/infective change with more focal peribronchial infective changes in the left lower lobe but no large established area of lobar collapse or consolidation.

c. <u>The Expert Opinion</u>

The Nurture expert's report (Appendix 4) states:

A decision was made to treat with intravenous antibiotics. Local and national antibiotic guidelines at that time proposed IV penicillin for tonsillitis. However, for the management of complications of tonsillitis (which should be considered in a child who remains unwell after 5 days of penicillin at home) such as bacterial tracheitis, retropharyngeal abscess and Lemierre's Disease, recommendations are for IV ceftriaxone plus metronidazole or IV co-amoxiclav. These antibiotic choices cover a broader range of pathogens including beta-lactamase producing pathogens and anaerobic pathogens which are commonly found in the nasopharynx. The ENT team appropriately added metronidazole to cover Lemierre's disease which can present with tonsillitis, thrombosis (clot) of the blood vessels in the neck and necrotising pneumonia. There was no radiological evidence at presentation of this condition, but it is appropriate to consider that this may be developing in a patient with severe tonsillitis not responding to first line treatments.

A throat swab sent on the 18th was reported at not showing haemolytic streptococci. Usually if other pathogens grow they would be reported. I cannot see a blood culture from admission in ED which would be best practice if starting IV antibiotics. Oral penicillin and erythromycin, as given in the community, may inhibit the isolation of organisms on both of these microbiological tests.

The medical teams documented on a number of occasions that there were reassuring features not consistent with sepsis (normal capillary refill time, urine output, warm and well perfused, moist mucous membranes). Softer indicators of severe infection were noted – raised neutrophil count, slightly raised lactate 2.58, raised glucose - but the platelet count, which may be a concerning feature for severe infection, was not commented on. The assessment of the admitting team (including 4 different physicians) was that this did not meet the threshold to cover for a severe bacterial infection. Wheeze is usually a symptom of a viral infection, and alongside a CRP of 40, this is likely to have suggested a viral aetiology. In addition, a chest x-ray showed mild changes in keeping with a viral infection. This was described in the medical notes as 'NAD' and usually this means there was no evidence of significant consolidation or pneumonia, pneumothorax etc. Admitting for observation and repeated assessment is a reasonable plan at this stage. It is not documented, but the lactate, potassium and glucose results may all be iatrogenic, that is, associated with the treatment of wheeze (corticosteroids and salbutamol).

The emergency department team responded in a timely manner instituting appropriate management of a child with tonsillitis and presumed viral lower respiratory tract infections. A more broad spectrum antibiotic would have been a reasonable addition to his treatment plan, but it is unclear whether this would have altered his hospital course. The paediatric emergency doctor clerking did not form an 'Impression' or 'Differential Diagnosis'. The paediatric SHO who clerked Yusuf had the impression of 1. 'tonsillitis' and 2. ' LRTI' (lower respiratory tract infection). The Paediatric registrar who reviewed him did not document an impression or differential diagnosis. The differential diagnosis informs appropriate investigations and treatment. Without considering possible differentials, it is impossible to ensure appropriate treatment pathways are followed. The differential diagnosis should be reviewed regularly during admission, in particular if the patient is not following an expected pathway to recovery.

d. <u>Conclusion from all the information available</u>

On the balance of probabilities, the presentation was no longer only tonsillitis as the primary diagnosis with 'red flag symptoms' were present which included that Yusuf's oxygen saturation was unable to be maintained without oxygen, increased work of breathing: tracheal tug, increased heart rate, respiratory rate and a temperature. This was considered to be a result of a viral lower respiratory tract infection.

In relation to the Emergency Department, there was an appropriate emergency response: The child was assessed, stabilised, and treated in line with the symptoms as they have presented.

His time in the Emergency Department was just over 7 hours, with initial triage being undertaken at the point of handover. Given the pressures on the Emergency Department at that time, this did not lead to any compromised care with proactive management from the point of admission. Nationally, the NHS England Operational Standard states that 95% of patients should be admitted, transferred, or discharged within 4 hours.

Admitting for observation and repeated assessment was an appropriate course of action, but a more structured approach to differential diagnosis would have strengthened the management plan.

The nursing care which commenced on the ED has been discussed in Appendix 5.

6. SCH: The Ward

18th – 21st November 2022

a. The Family Perspective

The family reported *that on The Ward, issues developed with Yusuf's cannula. The bandage around the cannula repeatedly got wet, and the nurse's assumed Yusuf was drooling on his hand. They had attempted to twist and turn the needle a little but hadn't fully rectified the issue with the cannula. Yusuf's cannula continued leaking over the weekend until Monday when his bed was wet.* Family photograph reviewed.

Saturday 19th November 2022

• *Yusuf began eating small amounts and drinking small amounts and was able to sit up a little. Prior to this Yusuf had been extremely drowsy and sleepy, with wake windows of about 15 minutes.*

Sunday 20th November 2022

• *Since Yusuf was admitted he consistently showed oxygen level readings of low 80's and remained on oxygen throughout.*

• *At this point doctors and nurses informed Yusuf's mum that his oxygen shouldn't be this low, and they are unaware as to why it is this low. They said they assume it is this low because of his severe tonsillitis combined with his chest infection.*

• *No x-ray was performed over the weekend.*

• *By Sunday afternoon, Yusuf's was again struggling to eat/drink.*

Yusuf's Mum kept the family informed of her continuing concerns and health care journey of Yusuf by WhatsApp messaging which are included in Appendices 4, 5 and 17 in detail.

b. The Medical Record

This has been summarised by the experts and used as the medical record is paper-based.

The reports from the Nurture medical experts are available in Appendix 4 and the Nurture expert nurse review in Appendix 5.

Nursing notes were available and entries were made summarising care on 18th November 2022 at 2300, 19th November 2022 at 01.45, 05.15, 13.30. 16.30. Then recommenced on the 20th November 2022 at 06.30, 10.30, 13.00, 1700 and 22.15.

In addition, medical records were available which included the reviews on the 18th, 19th and the 20th November 2022.

The Medical Experts stated that *The ENT team documented a plan for joint ENT-Medical care for Yusuf. He was written up for three times a day 0.15mg/kg dexamethasone for upper airway obstruction as per the ENT team. A first dose was given at 9pm. This would be a total of 0.75mg/kg dexamethasone in a day rather than 0.6mg/kg. A datix was recorded to investigate this by the nurses.*

Yusuf was reviewed by a senior registrar (ST8, about to complete training and become a consultant) at 23.30. The nursing staff had expressed concerns re stridor and increased work of breathing. On review, they noted that he was snoring, but without stridor (noise on breathing in due to airway obstruction in the neck). Oxygen saturations were 99% in 1 L low flow oxygen, RR 28 and HR 100, he was afebrile. There was good air entry with no wheeze on listening to his chest. They commented that he was settled, warm and well perfused at this point. The plan was to continue current care and to do a repeat blood gas as per previous plan. They did not document an impression, nor a differential diagnosis for Yusuf.

Overnight his oxygen requirement increased to 4L face mask oxygen following a reading of saturations of 95%. The maximum respiratory rate recorded was 32, with mild respiratory distress.

As part of factual accuracy SCH stated that Yusuf was changed to the face mask because the nasal cannula was uncomfortable so may not have been an increase in oxygen requirement which is documented in the nursing record.

He was reviewed by the ENT team at 9am who noted he was out of oxygen and swallowing better. They proposed he could be discharged once eating and drinking normally.

At 12.15 he was reviewed by the paediatric team on the post take ward round (PTWR); signed by the doctor which I interpret as Consultant. At that time his observations were within normal limits. Between 9 and 12, he had dropped his oxygen saturations to 88 and 89% while off oxygen and corrected with oxygen therapy. On examination, no wheeze was noted. There were ongoing nursing concerns re stridor and the plan from this review was to consider escalation of management of upper airway obstruction (budesonide/adrenaline

nebs). Iv fluids were discontinued as he was drinking well and his observations were stable. Electrolytes were improved on repeat. The CRP and white cell count were not repeated. The documented impression was stable. No differential diagnosis was documented.

20.11.22

ENT review – noted ongoing slough on tonsils. They noted the chest x-ray from 18.11.22 showed no consolidation and commented on the oxygen saturations and lack of stridor. They proposed weaning oxygen with a lower threshold for oxygen saturations (94-98%).

The nursing notes record that Yusuf did not tolerate nasal cannula oxygen so was left on face mask. They noted that he was coughing more. His observations (RR, HR and oxygen saturations) were stable.

The medical team reviewed at 12.10 which was undertaken by the medical team – ST6. They noted the oxygen requirement with no wheeze. The plan was to continue IV antibiotics and to wean oxygen. Not recorded, but I note that salbutamol treatment discontinued on the drug chart. They documented a differential diagnosis at the start of the note of tonsillitis and LRTI, but did not form an impression nor update the differential diagnosis at the end of the note. At this point despite resolution of wheeze, he remained in oxygen.

Family photographs from this day reviewed.

Nurse's notes in the afternoon comment on increase work of breathing, which subsequently settled. They also note his cannula tissued and was replaced. At 2am there were no concerns. The parents report that a doctor reviewed Yusuf between 2-3am, but this is not recorded by either the nursing or medical notes. The parents report that they were told his chest was clear at this time. There is a discrepancy between the parents report and video and the medical and nursing notes that I cannot explain.

The nursing care related to the cannula, administration of medication and escalation in relation to the changing clinical observations have been described in detail in Appendix 5 and included in the analysis below. This detailed analysis is supported by interview evidence and recommendations below.

c. <u>The Expert Opinion</u>

The Nurture medical expert report is available in Appendix 4.

Medical Opinion: *There was clinical improvement based on observations, clinical notes and parental photographs from the 18th-20th November. The wheeze improved and bronchodilators were discontinued. Despite this, he continued to have an oxygen requirement. The working diagnosis was of tonsillitis and a lower respiratory tract infection. The admission chest x-ray was suggestive of a viral infection, as was the CRP on the 18th. However, it might have been reasonable to re-assess on the 20th to understand why he*

still had an oxygen requirement in the absence of wheeze. There is a lack of documentation of differential diagnosis, or re-assessment of the cause for admission, oxygen requirement throughout his stay. Re-assessment might have included repeat bloods and a repeat chest x-ray. Based on the blood tests on the 21st, this may have shown a rising white cell count, but not a CRP. Whether this would have prompted a switch to broader antibiotic cover, and whether this would have changed the outcome is unclear. It is impossible to say whether chest x-ray changes might have prompted a change in antibiotics. Without more understanding of what caused the pneumonia, it is impossible to make a statement on whether IV antibiotics or earlier detection would have prevented Yusuf's death.

Documentation of who was present for each clinical review was not always clear.

Overall, there is no recorded evidence of medical reviews occurring due to raised PEWS scores as per recommended guidelines.

It is not clear from the documentation who the lead consultant responsible for this care was as both the ENT and Paediatric teams were making recommendations although as part of the Factual Accuracy and interviews, there was a lead consultant identified.

The admission medical notes show that Yusuf was seen by a member of the middle grade rota within 4 hours as per national standards.

In addition, they documented a discussion of the plan for the child as discussed with the on-call consultant. Yusuf should have been seen by a Consultant within 14 hours of admission. The documentation of the 'PTWR' (post take ward round) does not clearly state which members of the team saw him, although it appears to have been the consultant, the documentation should be easier to understand. This was just over 14 hours. Subsequent to this, the recommendation is that a consultant paediatrician holds a medical handover every 12 hours. This is not routinely documented in the notes. Yusuf was seen by a consultant at least once, but the documentation of who reviewed him and when is inadequate. He was seen by two clinical teams, best practice is to identify a lead consultant who is responsible for care, particularly when more than one team is involved in care (eg ENT and paediatrics).

Nursing Care has been summarised for ease of reading but include the following areas of concern.

- Vascular Access and Intravenous Therapy Review
- Paediatric Early Warning Score (PEWS and Escalation)
- Medicines Administration

- **Vascular Access and Intravenous Therapy Review (Appendix 5)**

The IV site was monitored but not in line with national standards and Visual Infusion Phlebitis (VIP) scores were recorded irregularly. The VIP Score is a clinical tool used to assess the condition of a peripheral intravenous (IV) cannula site. It helps healthcare professionals identify early signs of phlebitis (inflammation of the vein), infection, or complications related to cannula use.

Cannula insertions and fixation were not documented, contrary to RCN Standards for Infusion Therapy (2016). Trust guidelines (2022) were outdated (last review: 2015). Aseptic Non-Touch Technique (ANTT) was not integrated into guidelines and additional wrap-around bandaging was applied to all cannulas limiting visualisation.

Required hourly pump pressure and site checks were not documented.

VIP scoring was not performed 20-21st November during a continuous infusion or during drug administration preventing assessment of site integrity therefore leading to the possibility that IV antibiotics and IV fluids may not be administered effectively.

Pump serial numbers were not recorded, which limits retrospective analysis for incident investigations. There was no designated space in the fluid balance chart to record pump pressures, making compliance with trust guidelines impossible.

No documentation was present to confirm if bandaging was removed for drug administrations or for site assessments, raising concerns about effectiveness of IV therapy delivery.

We acknowledge the Trust's view, shared during the factual accuracy process, that IV administration was observed and believed to have been delivered. There are nursing entries such as at 02:15 on 21st November 2022 noting the cannula was "working well." However, in the absence of VIP scoring during the night shift of the 20th into the 21st November, documentation of direct visual site assessments, and clear evidence of cannula visualisation during drug delivery, it is not possible to confirm the ongoing integrity of the site with confidence or confirm how the assessment of functionality was assessed or undertaken.

- **Summary of PEWS Usage and Escalation (Appendix 5)**

The Paediatric Early Warning Score (PEWS) is a tool used to help recognise early signs that a child's condition may be deteriorating. It involves regular monitoring of key vital signs such as heart rate, breathing rate, oxygen levels, and a child's overall appearance or behaviour. Each observation is given a score, and the total score helps guide how closely a child needs to be monitored and whether senior review or urgent medical attention is required.

National guidance, including NHS England's *Paediatric Early Warning Score Standard*[31], emphasises that PEWS should support but not replace clinical judgement. It is designed to prompt staff to pause, review the full clinical picture, and consider escalation if a child's condition is worsening or not improving as expected. A higher PEWS score usually results in increased frequency of observations and may trigger a response such as notifying a doctor, initiating treatment, or moving the child to a higher level of care.

However, PEWS is not used in isolation. Clinical professionals are expected to apply their experience, knowledge of the child, and other contextual information when interpreting scores. In some cases, changes in the PEWS score may reflect a temporary or expected reaction to treatment (such as removing oxygen) rather than a sign of deterioration. When this happens, it is good practice for staff to document the reasoning behind their decision not to escalate, especially if the child's score increases but no medical review is sought.

In this review, we have considered both the numerical scores and the accompanying clinical and nursing responses. Where escalation did not occur despite elevated PEWS scores, we have looked for documented evidence of clinical judgement to understand the decisions made or that handover of this information was present. This is essential not only for learning, but also for ensuring that escalation protocols are used consistently and safely.

Trust guidelines for the use of the Paediatric Early Warning Score (PEWS) system and the recording of vital signs were in place and up to date at the time of Yusuf's admission. Observations were recorded using the CareFlow Vitals e-observation system and PEWS scoring was applied throughout their stay on Ward.

As part of factual accuracy SCH stated that Yusuf was changed to the face mask because the nasal cannula was uncomfortable so may not have been an increase in oxygen requirement. However, the Nurture medical experts and nursing experts confirmed that the clinical decision making in relation to Yusuf dependence on oxygen was poorly documented. PEWs remained the same despite the increase in oxygen so could be an additional indication of changing respiratory status.

We acknowledge the detailed clarification provided by the Trust regarding the use of PEWS scores, oxygen usage, and clinical decision-making between the 18th and 21st of November 2022. It is proposed by the Trust that professionals used their judgement to interpret PEWS in the context of Yusuf's condition, particularly in relation to oxygen tolerance. We also recognise that, in several instances, observations were repeated more frequently than the minimum required intervals, and that some scores increased due to periods without oxygen and reverted back to the previous levels. We also noted that the medical team identified that weaning oxygen permitted oxygen saturations of 94%.

[31] https://www.england.nhs.uk/wp-content/uploads/2023/11/pews-observation-and-escalation-chart-5-12-years-updated.pdf

Further evidence was again provided in Factual Accuracy

"There were four (not multiple) elevated PEWS which were not escalated to the on-call medic due to him responding to being weaned off oxygen.

- *19th 0744- PEW 7- tried out of O2 (did not require escalation)*
- *19th 07:56-PEW reduced to 4 when 02 reapplied*
- *19th 09:00 reviewed by ST3 ENT Dr*
- *19th 09:28- PEW 6- tried out of O2 (did not require escalation)*
- *19th 09:30- PEW reduced to 4 when O2 reapplied 2 mins later.*
- *19th 12:15- consultant review*
- *19th 15:46-PEW 7- tried out of O2 (did not require escalation)*
- *19th 15:47 PEW reduced to 3 when O2 reapplied 1 minute later.*

Although not written in nursing notes it is documented on the PEW chart that the oxygen had been removed and reapplied and PEWS were documented to support this."

However, our analysis reflects that the application of PEWS scoring and the documentation of the decision making in relation to escalation fell below the expected standard during this period. Specifically, there was inconsistency in the documentation that linked elevated scores to actions such as why he was tried out of oxygen, which was usually as Yusuf removed his mask from the statement made by the family on the 15th May 2025 albeit that weaning was also identified as the rationale in the factual accuracy. The putting on oxygen leading to improvement and limited documentation of the rationale for non-escalation and no additional documentation of handover to clinical teams particularly around oxygen dependency except the Careflow system is all poorly documented.

It is important to consider the clinical context. Yusuf was a previously well child, and repeated episodes of hypoxia should not be readily accepted as a normal or safe part of care without documented rationale especially in relation to lack of escalation. Although oxygen adjustments and PEWS fluctuations may fall within accepted clinical judgement, the repeated tolerance of desaturations without corresponding medical review or documentation risks creating a culture where deterioration is inadvertently normalised. While the nursing team are not responsible for diagnosis, there remains a professional duty to escalate when physiological parameters that breach safe thresholds, particularly in children with no prior respiratory compromise. The absence of clear documentation explaining the rationale for withholding escalation in these circumstances suggests a potential gap in shared understanding of what constitutes expected recovery versus clinical concern.

While some actions may have technically aligned with local standard operating procedures and that the ward round reviews were equivalent to an escalation point, the spirit and intent of PEWS, ensuring timely recognition and response to deterioration, was not consistently upheld.

Between 19th and 20th November, opportunities for appropriate clinical review in response to elevated PEW scores appear to have been considered acceptable. The PEWs at 00.02 on the 21st November was 6+ RR 42, O2 sats 100%, increased O2 to 7l/min, moderate respiratory distress, subcostal recession, tracheal tug and intercostal recession, HR: 121, 0 pain score, no concerns from mum recorded has been discussed further later in the report.

It is also noted that during this period, there was limited use of full observation sets, particularly capillary refill time and blood pressure despite being essential components when PEW scores are elevated. The last documented capillary refill time was on 18th November, and blood pressure recordings were sparse, with a significant gap between 19th and 21st November 2022.

Furthermore, the 'concern' field within the PEW scoring tool was consistently marked as ‘no concerns’, despite ongoing parental concerns being raised. According to trust guidance, parental concerns should be factored into PEWS scoring. The failure to document and account for these concerns may have led to an underestimation of the clinical severity.

- **Summary of Medicines Administration Appendix 5**

From Nurture Expert: *Metronidazole: A dose has been omitted at 20:00hrs on the 18th of November. The following dose was administered, but not at the time prescribed. It is unclear if this was discussed/communicated to the medical team. It is unclear if there was a reason as to why this dose was unable to be administered.*

After access was lost on the 20th of November, there was an inability to administer the doses of intravenous antibiotics due at the prescribed times, until venous access re-established. It is unclear if any discussions/communications were had regarding providing an alternative oral or intramuscular (IM) antibiotic cover, until venous access could be re-established. Metronidazole was administered 3.5 hours after the prescribed dose time and Benzylpenicillin was 2 hours after the prescribed dose time. This was an opportunity to review the prescription times and ensure that the times for administration were clarified moving forward to prevent any risk of confusion with times that intravenous therapy treatment was due.

Oral dexamethasone: This was prescribed at regular time intervals, but none of the doses administered were given at the prescribed times. This prescription should have been

discussed with a prescriber and re-written to prevent any potential for confusion and drug administration errors. Communications between the nursing and medical team regarding the administration times would have been beneficial.

Oromorph: It is noted that this was prescribed under 'regular prescriptions,' not 'as required prescriptions.' As a regular prescription this should be administered, as prescribed. To allow for nurse discretion the drug should be prescribed under 'as required prescriptions,' not as a 'regular prescriptions' with regular times for administration. This could be discussed with the prescriber, to establish if 'as required prescriptions' would have been more appropriate than 'required prescriptions.'

This prescription for Oromorph should have been discussed with a prescriber and re prescribed to eliminate the conflicting frequency (QDS)and times daily (TDS). Prescribing under the 'as required prescriptions' would allow for nurse discretion in administration, rather than under the 'regular prescriptions'. In addition, for additional safe practice, brand names should not be used on prescription charts.

Paracetamol and Ibuprofen: these prescriptions were prescribed at fixed times; this did not give staff the ability to be able to administer the doses for when Yusuf potentially would require pain relief. Having such fixed times which were only during the day did not allow for patient centred care and again doses were not administered at the times prescribed. Prescribing under the 'as required prescriptions' would allow for nurse discretion in administration, rather than under the 'regular prescriptions.'

d. <u>Supplementary investigation strategy (Appendix 17)</u>

The care overnight on 20th to 21st November 2022

This section presents a comparative analysis of documented evidence, staff interviews, clinical records, and family reports including the video of Yusuf taken from the family's evidence at 01.14 on the night of 20th to 21st November 2022. The aim is to identify where perspectives align and where discrepancies have been identified. The team had initially interpreted this video as having been taken at 07.41 when it accompanied a family WhatsApp message.

Our Nurture Experts state that *the short video clip demonstrates a child who has a prolonged expiratory phase and evidence of increased work of breathing. He has (based only on this short video clip) a respiratory rate of 32-36 which is raised for his age. He is sitting upright which is an unusual posture for a child to take and his breathing pattern is abnormal. His saturations are 93% and heart rate 137 in the background. He has no mask over his face.*

All Nurture experts state this should have led to an escalation. When this video was taken, Yusuf was demonstrating evidence of respiratory compromise.

Summary Table of Consistencies and Inconsistencies

CONSISTENCIES

Theme	Consistent with Triangulation
When the video described above was shown to staff.	Multiple interviews including the Nurture experts confirmed moderate to severe respiratory distress was seen in the video This was identified as requiring escalation.
Timing of Medication	The medication was given as recorded in the clinical record, although not always at the time prescribed. Detailed analysis is difficult when acute presentations are being managed as often the records are written retrospectively but mum stated five nebulisers were given and this is consistent with the medicines administration charts.
Escalation at 07:30am	The clinical records identify this was the key point of initial escalation which was confirmed by multiple sources.
ENT Review Timing	ENT review timing at 0900 confirmed by multiple sources.
The Day Team: Doctor Attendance and Escalation post 0900	The Day Team: Doctor's account and actions were corroborated across documentation and agreed with Yusuf's family that occurred after 0900.
Prior to admission to PICU	Yusuf's condition significantly worsened over the course of the morning with difficulty in cannulation, reduced urine output, and signs of clinical deterioration and this was accurately documented and confirmed by Yusuf's mum.

INCONSISTENCIES

Theme	Inconsistent
Cannula Leak	Mum's account, photos, and fluid chart support the cannula leak and possible compromise.
Doctor Attendance Overnight (2–3am)	Mum reports a doctor being seen at 2–3am; All staff interviewed state they did not see Yusuf at this time. There is no clinical records of any attendance at this time. In addition, nursing staff were reviewed and no contact with Yusuf was identified from any member of the nursing or clinical team.
PEWS vs Video Evidence	PEWS recorded 2+ at 01.04 but video shows clear respiratory distress at 01.14. PEWS is with oxygen on and the video is without oxygen
Nurse-in-Charge Awareness on Night Shift	Nurse-in-charge was not aware of any escalation overnight however the interview was taken over 2 years since the incident. Having reviewed the video two years after the event, the nurse responsible for Yusuf recalled that she did escalate. Although, accounts varied between her statements.
On Call Night Doctor Awareness	The first time the on call night doctors became aware of the escalation was at 7.30am according to their medical records and interviews. This is inconsistent with Yusuf's mum's statement.
Parental Reports vs Clinical Notes	Mum reported not being listened to; notes and interviews report no concerns from mum during the night time, however, all clinical records from 0700 stated mum had said that 'WOB has been worsening' and this was confirmed in the WhatsApp messages.
Pain and Sleep Perception	Mum says Yusuf couldn't sleep. WhatsApp messages also include 'He had such a hard night. With breathing and pain' Nursing notes describe him as 'settled and asleep except for short periods when he was experiencing pain. There was increased WOB when in pain'.
Mum did not speak to a doctor from 04.30 to 05.00	The On Call Night Doctor states she spoke to mum by the nurse's station but did not examine Yusuf and was not made aware of Yusuf so this was a casual conversation for reassurance. This was consistent across an initial interview and further statement.

Detailed Analysis of 07:45 Doctor Review of Yusuf

Theme	Findings	Inconsistent or Conflicting Evidence
Timing of On Call Night Doctor's Arrival	Nurse reports the On Call Night Doctor as bleeped around 07:30 and responded quickly; treatment started soon after.	Mum states she does not believe Yusuf was seen by a doctor around 07:45.
Clinical Actions Taken	The On Call Night Doctor states she examined Yusuf at around 07.45 but could not be accurate about the time, gave verbal orders for nebulisers, which were administered and prescribed further medication	Mum's WhatsApp at 07:42 records no doctor had yet attended. 'Doctor gna come later haven been yet'
Documentation Timing	Notes and meds chart confirm On Call Night Doctor involvement starting between 07:30–08:30 with written and signed entries in multiple documents which includes the examination of Yusuf at 07.45	Dr acknowledged timings were written retrospectively so may not be accurate, this is consistent with usual practice
Nurse Account	Nurse recalls On Call Night Doctor attending quickly and prescribing nebulisers.	
WhatsApp Record Timeline	Messages support the worsening presentation which was perceived by the nurse on duty and by all daytime staff, both nursing and clinical WhatsApp: Feel like he is getting worse He had such a hard night With breathing and pain	
Nebuliser Timing	Meds chart supports treatment occurred approximately 08:15, 08:30. The On Call Night Doctor prescribed these.	In WhatsApp Messages a picture of a nebulisers at 08.45 and 08.50.
Whatsapp Record Timeline	At 07.45 Night doctor did come have a look Just listened into chest and said it doesn't sound wheezy	The On Call Night Doctor has stated she saw Yusuf at 07.45 Yusuf's mum has stated that the WhatsApp

	At 07.50 Just giving him painkillers now Doc gna come in a bit init	Message is related to an earlier visit of the doctor.
ENT attendance	ENT references commencement of nebulisers and states: Note medical overnight R/V – for WR R/V med reg. This would be the on Call Night Doctor who was the medical overnight review.	
Medical Handover	The On Call Night Doctor escalated her concerns during the medical handover and requested that Yusuf be prioritised for further review. This was corroborated by The Ward Doctor, consultant, and On Call Night Doctor, who all recall that Yusuf was specifically identified as needing to be seen urgently and The Ward Doctor was prioritised to attend The Ward.	
The Day Team: Doctor	The Day Team: Doctor stated that she was comforted by the fact that ENT had already seen Yusuf and that The On Call Night Doctor had commenced salbutamol. The Day Team: Doctor discussed that she might have stated that she was surprised as this was an unusual presentation and he had clearly been in hospital for over 48 hours and he was not getting better.	Mum felt that The Day Team: Doctor had asked if he had been like this during the night and if he had been seen by a doctor. She repeated the same questions at least three times and appeared visibly shocked by presentation.

7. SCH: The Ward and their escalation

a. The Family Perspective

The family reported *that on The Ward, issues developed with Yusuf's cannula. The bandage around the cannula repeatedly got wet, and the nurse's assumed Yusuf was drooling on his hand. They had attempted to twist and turn the needle a little but hadn't fully rectified the issue with the cannula. Yusuf's cannula continued leaking over the weekend until Monday when his bed was wet.* Family photograph reviewed.

• *Sunday night Yusuf's breathing significantly worsened, and he began complaining of severe pain in his abdominal area.*

• *During the night, Yusuf was seen to by a doctor at approximately 2/3am. The doctor listened to Yusuf's chest and said his chest is clear, and he did not need nebulisers.*

Monday 21st November 2022

Family photographs and videos reviewed.

• *At approximately 10am, another doctor examined Yusuf. She was not content with his breathing and asked whether a doctor had seen him in the night like this. Mum told her that he has been examined in the night, and the doctor in the night said his chest was clear. The doctor then gave Yusuf a nebuliser and was very concerned about Yusuf's breathing, stating that he is trying too hard to breathe.*

• *The doctor then called for immediate help from other doctors.*

• *Yusuf's family were informed that Yusuf's infection had spread, and he had developed pneumonia. They explained that they now have three infections to deal with, so they will take over his breathing so that they can focus on treating the infections.*

• *The doctors then used alternative medication, and shared that if this medication was not effective then they would need to take him to ICU.*

• *A chest x-ray was performed*

• *Approximately 20 minutes later it was decided by the doctors that Yusuf should be taken to the ICU to be monitored closely.*

• *Upon arrival at the ICU, Yusuf was given oxygen, and later in the night at approximately 8pm Yusuf was put onto the ventilator.*

Yusuf's Mum kept the family informed of her continuing concerns and health care journey of Yusuf by WhatsApp messaging.

b. The Medical Record

This has been summarised by the experts and used as the medical record is paper-based.

The reports from the Nurture medical experts are available in Appendix 4 and the Nurture expert nurse review in Appendix 5.

On 21st November, the records were completed at 02.15, 06.30, 13.10 (written in retrospect of the day) and then on transfer to PCCU.

In addition, medical records were available which included the series of medical reviews on the 21st November 2022 commencing at 08.15.

21.11.22 6.30am Nursing team document the need for multiple pain relief overnight and an increase in work of breathing, but stable observations. On review of the observation chart, the observations (HR, RR, oxygen saturations) and recorded work of breathing were stable until just before 8am.

Nursing note written in retrospect for 07.30 reports moderate work of breathing and asks for a medical review.

Yusuf at this time point is demonstrating evidence of respiratory compromise and the nursing staff asks for a medical review.

08.15 Night doctor review (ST2). They document that he is complaining of chest tightness and pain on breathing, and that Mum reports worsening work of breathing overnight. His HR has increased compared to the last 24 hours (118) and respiratory rate is 32. They record a 'tight chest' with fine wheeze and prescribe 'burst' therapy (bronchodilator therapy with salbutamol and ipratropium). This resulted in better air entry and he is re-commenced on hourly salbutamol treatment. They do not record an impression or a differential diagnosis for the deterioration.

09.00 ENT ward round notes that the paediatric team should review the abdominal and chest pain. There is ongoing exudate on the tonsils and multiple small lymph nodes in the neck. They document a differential diagnosis of tonsillitis and LRTI/asthma.

09.30 day team review – note abdominal and chest pain with very abnormal observations (tachycardia, tachypnoea and low oxygen saturations). The impression is of a severe acute exacerbation of asthma with life-threatening features. An appropriate plan for escalation is made including intravenous access, bloods, blood cultures, chest x-ray, IV hydrocortisone and bronchodilator therapy with a reassessment every 20 minutes. Further reviews at 10.20, 10.40, 11.40 (with consultant) noted no significant improvement. A chest x-ray showed concerning right sided changes of pneumonia. A blood gas at 10.36 had a normal lactate (1.25), raised glucose (11.9), raised bicarbonate (31.8) with no evidence of acidosis (pH 7.34, BE 4.9) and mild electrolyte changes sodium 148, potassium 3.04).

His antibiotics were escalated to cefuroxime and metronidazole. Potassium was added to the intravenous fluids. He was given an adrenaline nebuliser and a magnesium sulphate infusion. An urgent PCCU review was requested.

Bloods at this time showed a CRP of 28, albumin of 30, white cell count of 46 and neutrophils of 43, haemoglobin of 113, platelets of 78. Renal and liver function were largely unremarkable.

12.45 Transfer to HDU

c. <u>The Expert Opinion</u>

The Nurture medical expert report is available in appendix 4.

The report states: *Based on the blood tests on the 21st, this may have shown a rising white cell count, but not a CRP. Whether this would have prompted a switch to broader antibiotic cover, and whether this would have changed the outcome is unclear. It is impossible to say whether chest x-ray changes might have prompted a change in antibiotics.*

Increased use of analgesia was noted by the nursing team on the 20/21st night. In retrospect this was likely pain due to a worsening pneumonic process. The recorded observations (heart rate, respiratory rate, oxygen requirement) did not show a clinical deterioration in the nursing record. It would have been appropriate based on the parental report of worsening cough, and the increasing need for pain relief to request a medical review, even in the absence of the video and PEWs scores overnight. The parents report that Yusuf was reviewed by a doctor, but there is no documented review by either the medical or the nursing team.

From the notes and observations, it appears that Yusuf deteriorated rapidly or decompensated on the morning of the 21st, Yusuf was identified to have features of a severe exacerbation of asthma. The team responded appropriately with treatment for wheeze. His PEWS score was between 4 and 8 over the hours of 8am-12pm and as per local guidelines, the team applied ward level interventions (bronchodilators, IV hydrocortisone, MgSO4, Adrenaline nebs etc), then consultant review and escalation to paediatric critical care.

The blood test results on the 21st were suggestive of a leukaemoid reaction (low CRP, low platelets, high white cell count) which is strongly associated with infections, in particular pneumonia. Corticosteroids may contribute to a leukaemoid reaction (as above, they can result in an increase in the white cell count). In a study of 656 children with a leukaemoid reaction, 40% had a previous clinically significant medical condition, most commonly asthma, prematurity and underlying genetic conditions. A leukaemoid reaction is associated with a longer length of stay of hospitalisation, but not increased mortality, unless associated with subsequent diagnosis of leukaemia.

- **Triangulation of Evidence from Interviews**

Interaction of Medical Staff and Yusuf on the 21st November 2022

We acknowledge that at the outset of this investigation, there was some uncertainty regarding which doctors were on duty during the night of 20th–21st November 2022. As part of our evidence-gathering process, we requested this information from Sheffield Children's Hospital (SCH), which provided the relevant rotas and names of staff without delay. It is important to note that this request was made later in the investigation, as our review followed a structured, chronological analysis of events.

Following the identification of medical staff, we requested interviews with all doctors involved in Yusuf's care, including where no medical entry had been recorded.

Yusuf's mother recalls that a doctor examined her son between 2:00am and 3:00am, listening to his chest, and a review by a night doctor was included in her 'WhatsApp message' written that morning. This was further confirmed in an interview. She has no recollection of speaking to a doctor at any point in time until 09.00 when seen by the ENT team and subsequently by The Day Team: Doctor.

In contrast, the On Call Night Doctor, recalls speaking with Yusuf's mother at around 5:00am to offer reassurance. This occurred near the nurses station and she did not come into any contact with Yusuf. An initial telephone interview and the statement written were consistent although the interviewer had not documented where the doctor was positioned in the initial interview. The doctor did not document this interaction as it was not considered clinical contact which is consistent with usual practice. She confirmed that she later reviewed Yusuf at around 07:45am after being bleeped at 07.30am and prescribed medication, with documentation completed and present in the medical record.

The page completed by The On Call Night Doctor was the reverse of a page and on the front side had the sticker on and as a reverse page, no identifying features.

SCH have confirmed that there is no record of the interaction between 0200-0300 and that all other doctors on duty have no recollection of any interaction with Yusuf at this time or any other time until 07.30am. The nurses were also requested whether they had interacted with Yusuf overnight but no individual has been identified outside those in the medical and nursing records.

Yusuf's mother does not have any recollection of seeing The On Call Night Doctor at 07.45, however the detailed analysis above has provided evidence that The On Call Night Doctor was the initiator of treatment, prioritised Yusuf at handover to be seen first by The Day Team: Doctor and was referred to within the nursing notes and ENT notes written at the time on the 21st November 2022.

The family remain confident in their account and has expressed concern that this difference in recollection reflects a missed opportunity for intervention. They were also disconcerted that the Trust was unable to confirm the identity of the doctor present overnight.

As the investigating team, our role is to document the available evidence and reflect all perspectives fairly. We recognise that this uncertainty is distressing for the family and the staff, and we include the description of the consistencies and inconsistencies to ensure transparency about the care provided.

d. Staffing Levels and Skill Mix – see Appendix 7

e. Conclusion from all the information available

We recognise the challenges that investigating an incident over 2 years after the initial events has provided challenges from all parties.

The care provided across the weekend did not meet the standards to be expected on The Ward.

There were significant gaps in nursing care in relation to the documentation of the use of PEWS and the associated escalation pathway during Yusuf's admission between 19th and 20th November 2022, which fell below the expected standards. This includes delayed or absent escalation (although was possibly compliant with local processes), missed opportunities for reassessment, inconsistencies between clinical documentation and nursing observations, and inadequate use of full vital sign sets.

Overnight on the 21st November 2022, at midnight, the PEWS was identified as being 6+, the nurse undertaking the observations has been inconsistent in her account of whether she escalated or not. It is important to recognise that this is over 2 years later. She did believe that the video taken of Yusuf reflected his presentation at the time. She has stated in her statement that this was escalated to the nursing and medical team. As a nurse, who had completed her preceptorship and had over 1 years post registration experience, she was relatively junior and the experienced Band 6 who was in charge of the ward had no recollection of seeing Yusuf as he was presenting in the video, and was not aware of the escalation of Yusuf. It is important to note, however that this was over 2 years since the events when the interview was undertaken. Placing Yusuf back on oxygen, then reducing the PEWs score was the care plan for Yusuf that was stated in the factual accuracy process. There is no supporting documentation for escalation or any subsequent review.

The On Call Night Doctor stated she had no contact overnight with Yusuf, although spoke to Yusuf's mum. The consultant on duty overnight, further confirmed that there had been no escalation. Further interactions were undertaken by the nursing team overnight show an improving picture recorded in the nursing records although the recording of PEWS did not integrate the presentation of worsening pain or the concerns of mum. Even if his

presentation was not as the video depicts, these additional factors should still have led to escalation overnight to the medical team.

The On Call Night Doctor stated if she had assessed Yusuf earlier and the clinical picture had been the same as seen in the video, she would have instigated the treatment and escalation that occurred later that morning.

This was further compounded by a failure to meet the standards for the management of cannula and provision of IV interventions and medicines management in accordance with best practice.

The Nurture medical experts describe in Appendix 4: *Yusuf responded to the initial treatment and demonstrated a clinical improvement. Earlier re-assessment of an ongoing oxygen requirement with a repeat chest x-ray and bloods may have identified a developing pneumonia sooner, however, the absence of worsening fever, respiratory rate and heart rate were potentially falsely reassuring. It is possible the appropriate use of corticosteroids to treat airway obstruction and severe tonsilitis masked the development of a bacterial pneumonia. Given the initial presentation of a viral infection, then a subsequent deterioration with pneumonia, this may represent a secondary bacterial infection following a viral infection.*

There is a lack of documentation of differential diagnosis, or re-assessment of the cause for admission and persistent oxygen requirement throughout his stay. Re-assessment might have included repeat bloods and a repeat chest x-ray. Based on the blood tests on the 21st, this may have shown a rising white cell count, but not a CRP. Whether this would have prompted a switch to broader antibiotic cover, and whether this would have changed the outcome is unclear. It is impossible to say whether chest x-ray changes might have prompted a change in antibiotics. Without more understanding of what caused the pneumonia, it is impossible to make a statement on whether IV antibiotics or earlier detection would have prevented Yusuf's death.

Family Questions

1. *Was there an overdose of medication and if so what was the medication? If an overdose occurred, what was the possible consequences to Yusuf?*

2. *Did the overdose impact on the blood sugar levels of Yusuf?*

3. *Was the overdose a contributing factor to Yusuf death?*

4. *Was harm occurring from dexamethasone dose?*

Our Nurture Medical Expert stated:

There was a drug error whereby an extra dose of dexamethasone was given. This is unlikely to have caused harm. The initial raised glucose may have been related to dexamethasone given in ED, or to have been a stress response. The team appropriately

considered whether this was possibly diabetic ketoacidosis and made a plan to monitor this, on discussion with the on-call diabetic lead.

Dexamethasone and other corticosteroids given for pneumonia or lower respiratory tract infections are known to improve outcomes. Corticosteroids are routinely given as management of both upper airway obstruction and wheeze, as well as hypotension associated with sepsis. In severe infections and sepsis, hypoglycaemia (low blood sugar levels) is associated with poor prognosis and outcomes. On the other hand, stress hyperglycaemia is relatively well recognised. Stress hyperglycemia is due to elevated cortisol, glucagon, growth hormone, catecholamines, and various cytokines, which stimulate glycogenolysis and gluconeogenesis, resulting in a transient increase in blood glucose concentration that typically normalizes when the stress abates. It may also in this case have been associated with the use of dexamethasone.

Respiratory illness, including asthma, is commonly associated with a stress hyperglycaemia response. A total daily dose of 0.75mg/kg/day is not an excessive dose although higher than the BNF recommended dose.

Dexamethasone was given at 0.75mg/kg/day on 18th and then 0.45mg/kg/day on 19/20 and then discontinued (equivalent to 5mg/kg/day and 3mg/kg/day respectively).

Patients taking glucocorticoids may not manifest common signs and symptoms of infection as clearly, due to the inhibition of cytokine release and the associated reduction in inflammatory and febrile responses leading to a failure in early recognition of infection. The adverse effects of corticosteroids are dose and duration dependent. The dose and duration which increases the risk of infection is unclear, but national recommendations for different management of infectious exposures (eg COVID, Chicken pox) are all based on more than 2 weeks treatment. In trials and observational studies, children who receive 3-5 days of treatment for asthma do not demonstrate an increased risk of infections compared to controls, but do see short term benefits as measured by length of stay and severity of disease if there is a history of previous wheeze or asthma[32].

Repeat bloods were sent on the 19th which confirmed an improvement of the electrolytes. The CRP and full blood count were not repeated. As the platelets were low and white cells raised on admission, this might have been good practice. Yusuf was afebrile following admission from ED (spiked to 38.1 during initial assessment). In addition, there were no clinical indications that he was not responding to the antibiotics he was on, or that there was worsening infection/sepsis (his tachycardia and tachypnoea improved, his blood pressure was stable and he was warm and well perfused and drinking/passing urine). The next set of bloods on the 21st showed that the CRP had fallen from 40 to 28. If there had been progressively worsening bacterial infection from the 18-21st, we might expect this to have increased. However, his white cell count had increased to 46 with neutrophils of 43. The platelet count was still low at 78. He had completed three days of dexamethasone as

[32] https://www.thelancet.com/journals/lanres/article/PIIS2213-2600(24)00041-9/fulltext

part of upper airway management which may have contributed to the rising white cell count (a recognised phenomenon). As above, it is possible, but unlikely, that the short course of steroids resulted in the lower CRP level and absence of fever.

5. *Did the medical team, on the night of 20th November and early morning of 21st November' respond to the concerns that Yusuf's mother had including the inconsistencies of medical opinion? Why did this occur?*

I cannot find any evidence that this review happened. The recorded observations during the night of the 21st did not indicate a change in his condition until the morning. There is a discrepancy between the parents report and video and the medical and nursing notes that I cannot explain.

There is no recording of a review, however based on the change in his painkiller requirement and parental concerns this would have been a reasonable thing to do. The recorded observations in the nursing record were however reassuring so it is unclear whether this would have altered the management and course of illness.

6. *Why was there a delay in reviewing Yusuf Xray of need to check what was x-rayed but likely to be chest. Did this delay contribute to Yusuf's outcome.*

The family note a delay in reviewing the x-ray from the 18th November and asked if it had been reviewed prior to the 21st, whether this would have demonstrated the severity of the presentation and changed the course.

Our Nurture Medical Expert states:

Chest x-ray 18.11.22 review – the paediatric ED doctor and the ENT doctor both comment on this chest x-ray in the notes. The ED doctor commented that it was 'NAD'. The ENT doctor commented that there was no consolidation. Although not explicitly documented this will have informed the antibiotic choice as there was no clear evidence of bacterial pneumonia and no features of necrotising pneumonia as seen in Lemierre's Disease. Based on this, there was no indication for different management which could have altered the outcome. The chest x-ray was reviewed by the treating doctors on the 18th and there was no indication for a change in management that could have changed the course of the illness. The formal radiologist report on the 19th confirmed their assessment.

7. *Was there consultant paediatric cover on the weekend in question? If yes, what was there involvement in this case? If no, did this fall below the level of staffing expected?*

From Factual Accuracy review: Full medical staffing is available in Appendix 7 and further explored in the questions below.

At all times there is a named medical consultant on call who is responsible for the care of patients on the ward and leads consultant handover at weekends.

- *The current weekend rota pattern is:*

Consultant A – Friday from 4:30pm to Sat 1pm

Consultant B – Saturday from 9am to Sunday 1pm

Consultant A – Sunday from 9am to Monday 1pm

SCH themselves stated:

We do think there is room for improvement in the way that consultant oversight is documented, as the majority (if not all) patients are discussed at the weekend handover (at midday), even if the patients were not seen directly by the consultant. There is no easy way to document this handover as it currently happens remotely to the patient and notes.

8. *What were the staffing levels on the Paediatric ward at the time Yusuf was being assessed. This includes the what skill mix was present, ie what band or grade of staff were on duty.*

From the Nurture expert report – Appendix 7 includes the information below about staffing including skill mix:

Planned numbers are based on 100% occupancy.

Staff shifts patterns were: 07.00 hours to 19.30 (Day Shift) and 19.00 hours to 07.30 hours (night shift).

*On the **18th November 2022**, there was 91% bed occupancy on the day shift and 83% occupancy on the night shift.*

Planned staff on the day was five Registered Nurses, actual staffing was five. Skill mix was two Band 6 registered nurses, three Band 5 registered nurses. Two additional registered nurses were rostered who were not in the numbers (supernumerary). On the day shift there was a Band 7 registered Nurse on duty, this was highlighted on the off duty as being a management day. In addition to this there were also three Band 3 Health Care Assistants on duty.

With regard to clinical skills, three members of staff were trained to administer intravenous drugs and fluids, four members of staff were Paediatric Life Support competent (PLS) and one member of staff was European Paediatric Life Support competent (EPALS).

On the night shift there were two Band 6 Registered Nurses, three Band 5 Registered Nurses. There was also two Band 3 Health Care Assistants on duty.

With regard to clinical skills, two members of staff were trained to administer intravenous drugs and fluids, two members of staff were Paediatric Life Support competent (PLS), and two members of staff were basic life support trained (BLS).

*On the **19th November 2022,** there was 83% occupancy on the day shift and 79% occupancy on the night shift.*

Planned staff on the day was five Registered Nurses, actual staffing was one Band 6 Registered Nurse and four Band 5 Registered Nurses. There was also two Band 3 Health Care Assistants on duty.

On the night shift planned staff was four registered nurses, actual staffing was three. This consisted of one Band 6 Registered Nurse, two Band 5 Registered Nurses. There was also two band 3 Health Care Assistants on duty.

With regard to clinical skills, two members of staff were trained to administer intravenous drugs and fluids, one members of staff was Paediatric Life Support competent (PLS) and three members of staff were basic life support trained (BLS)

*On the **20th November 2022,** there was 79% occupancy on the day shift and 75% occupancy on the night shift.*

Planned staff on the day shift was five registered nurses, actual staffing was four registered nurses. This consisted of one Band 6 registered Nurse and three Band 5 Registered Nurses. There was also three Band 3 Health Care Assistants on duty.

With regard to clinical skills, two members of staff were trained to administer intravenous drugs and fluids, four members of staff was Paediatric Life Support competent (PLS), and three members of staff were basic life support trained (BLS).

On the night shift planned staff was four registered nurses, actual staffing was four. This consisted of one Band 6 Registered Nurse, and three Band 5 Registered Nurses. There was also two Band 3 Health Care Assistants on duty.

With regard to clinical skills, three members of staff were trained to administer intravenous drugs and fluids, one member of staff was Paediatric Life Support competent (PLS), and five members of staff were basic life support trained (BLS).

9. *The cannula was considered to be leaking, was the cannula sited correctly? Was the cannula patent? Should the cannula be replaced?*

The cannula was considered to be leaking and in Appendix 5, this is covered fully.

10. *The nurse on duty over this weekend was perceived not to respond to the distress that the family were experiencing, respond to their requests for help or identify that Yusuf's condition had worsened over the weekend. Why was this?*

The nurses including those who had been overseeing Yusuf's care over the weekend until the night shift on the 20th to the 21st felt Yusuf's condition did not require any additional interventions or that his condition and did not feel they had ignored any requests for help.

The family expressed concerns regarding continuity of care and a lack of oxygen monitoring.

The Nurture medical expert's state: '*The notes provided demonstrated regular monitoring of oxygen levels and other observations including respiratory rate, heart rate and work of breathing. As above, some of these parameters improved, while Yusuf remained in oxygen despite attempts to wean'. There was ongoing monitoring of routine observations including oxygen saturations. Re-assessment of the diagnosis based on the persistent oxygen requirement may have prompted different investigations and treatment.*

It is also noted that the escalation processes were not followed effectively so a PEWS score which was raised should have led to more regular reviews. This should include a medical review but this did not occur across the weekend of the 18th to 21st November and the experts felt the routine ward round was not an alternative for escalation.

The family expressed concern about a review in the early hours of the 21st by a junior doctor, which was inconsistent with the review, later in the morning of the 21st.

The accounts from the doctor and family members differ and is discussed above.

The family expressed concerns that Yusuf was not seen by a consultant between 18th and 21st November. They also expressed concerns regarding the experience of the medical staff available during the stay.

From the Nurture medical experts: '*The admission medical notes show that Yusuf was seen by a member of the middle grade rota within 4 hours as per national standards.*[33] *In addition, they documented a discussion of the plan for the child as discussed with the on-call consultant. Yusuf should have been seen by a Consultant within 14 hours of admission. The documentation of the 'PTWR' (post take ward round) does not clearly state which members of the team saw him, although it appears to have been the consultant, the documentation should be easier to understand. Subsequent to this, the recommendation is that a consultant paediatrician holds a medical handover every 12 hours. This is not routinely documented in the notes. Yusuf was seen by a consultant at least once, but the documentation of who reviewed him and when is inadequate. He was seen by a two clinical*

[33] Facing the Future - standards for acute general paediatric services | RCPCH

teams, best practice is to identify the lead consultant who is responsible for care, particularly when more than one team is involved in care (eg ENT and paediatrics).

The care in PCCU has not been analysed further in the main report however has been considered in the Expert Report: Appendix 4.

The care and treatment of Yusuf in PCCU was proactively undertaken in line with evidence-based standards and revealed no significant concerns.

The experts identified that they were not experts in PCCU but the Terms of Reference were not focussed on this area of care. If further expert opinion is required the Terms of Reference would need extending.

Other Areas

Review of other areas in relation to Yusuf

11. Statement on Scope and Sensitivity Regarding Death Certification

We recognise that the death in question was profoundly traumatic for everyone involved, including the family and the professionals who cared Yusuf. This event occurred in 2022, prior to the implementation of the statutory Medical Examiner system in England and Wales. The Medical Examiner role now provides an important layer of clinical scrutiny, supporting both the quality of death certification and the work of coroners.

At the time of this death, processes were shaped by the legacy of the COVID-19 pandemic and significant workforce pressures, particularly in paediatric pathology. Additionally, the case spans more than one jurisdiction and touches on matters of cultural sensitivity and the profound impact of bereavement.

Given the scope and terms of reference of this investigation, and out of respect for ongoing statutory responsibilities and the limits of our remit, we will not be examining decisions specifically relating to the completion of the Medical Certificate of Cause of Death or any subsequent coronial determinations. These processes sit within a separate legal framework, and it is appropriate that any concerns regarding them be addressed through the appropriate statutory channels. In Appendix 14, SCH provided a reflective statement in relation to this matter.

Our focus remains on understanding the systems, values, and practices surrounding care, and supporting compassionate learning for the benefit of future families and professionals.

12. Research Trial: Pressure Study

1. <u>The impact on the family</u>

The family were informed that Yusuf had been the subject of a PRESSURE study. The family reported that Yusuf participation in this study was raised to them following his death. The family stated that they were not asked for their consent for Yusuf to participate in this study, however, when SCH asked them to provide retrospective consent via a form sent to the family, after his death in a letter dated 14 July 2023, this was confusing. The family remain concerned about the inconsistent information it has received regarding Yusuf participation in the study and seek clarification in this regard.

An example of the inconsistent information is that the family state they were informed over the phone that Yusuf was part of the other study group and then it was corrected. This further undermined the confidence of the family in Yusuf's overall care.

2. Family Question

There is a lack of consistency about whether Yusuf was in the subject of a 'pressure study'. If Yusuf was a participant in the study, why was the policy in relation to research and consent not followed? If no, why were the family informed about Yusuf's participation in this study.

Yusuf had been enrolled into a Pressure Study. The PRESSURE trial is a national study (funded by the NIHR and led by Cambridge University Hospitals NHS FT) being conducted across many Paediatric Intensive Care Units across the country. Sheffield Children's is one of the participating centres. The study protocol, which has NHS Research Ethics Committee and Health Research Authority approval, had been implemented across all participating sites.

https://www.icnarc.org/research-studies/pressure/for-patients/

There was significant parent consultation during the design of the trial as the study utilises a model called 'research without prior consent' due to the emergency nature of the situation at the time of randomisation of participants. In accordance with the protocol, participants must be randomised within 6 hours of starting inotropes and so it is recognised that at this point the patients will be very sick. This model is a well-used approach to research in critical care and emergency department research.

Yusuf was randomised to the PRESSURE trial on 22 November 2022 not long after being admitted to the PCCU at SCH as he met the inclusion criteria of the trial and none of the exclusion criteria. Yusuf was randomised to the trial as per the protocol. There are two arms to the study and Yusuf was randomised to the 'standard of care' arm and therefore being part of the trial didn't alter his treatment which was documented in his medical notes and included that 'the parents weren't onsite at the time of randomisation'. Yusuf then deteriorated quickly and passed away before there was an appropriate time to approach the family about the study.

The protocol suggests that families should be posted the information about the study at 4 weeks post bereavement. If no response is received from the family, then a further letter is sent 4 weeks after this date. If no response is received, the patient's anonymised data is then used in the study.

Following Yusuf death, there was a discussion about the best approach in relation to notifying his parents about the trial 4 weeks post bereavement. The team felt that it would be more appropriate to discuss the study with the family during their bereavement follow up meeting which is offered routinely (usually around 8 weeks) rather than send a letter 'out of the blue'. This was discussed with the national PRESSURE research team who supported the local decision.

Unfortunately, they did not consider what to do if the family did not attend the follow up bereavement meeting.

In July 2023, it was recognised that the family should be informed about the study and so the decision was made to send the initial set of documents about the PRESSURE trial to the family with a covering letter to explain the delay in sending this information to them. The study information was re-sent in mid August 2023.

The research team heard back that the family did not want Yusuf included in the research.

This was confirmed by the national PRESSURE study team that Yusuf and his data would NOT be used in the trial.

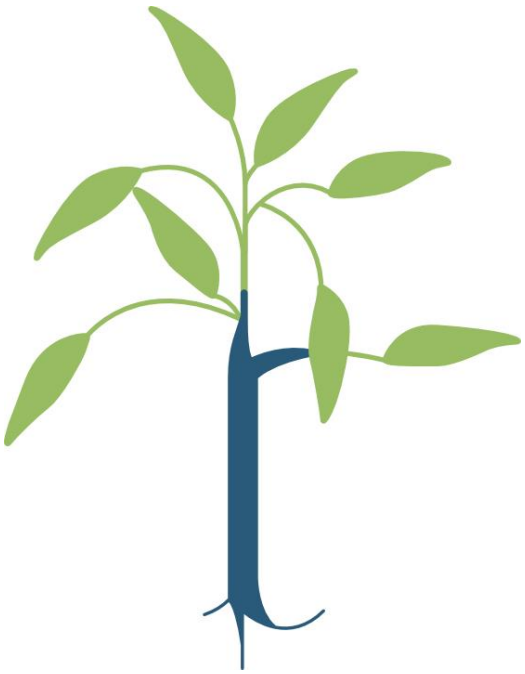
The team recognised this had led to additional distress for the family and had altered their processes.

3. The Expert Opinion

Our experts recognised the impact on Yusuf and his family of the delay in communicating his participation but wanted to ensure that this did not have a negative impact on future studies. They have been involved in multiple deferred consent studies and note multiple publications on the benefit they bring to children and young people and felt that this process should continue as this information from these studies enables better treatment for children and young people.

Learning from this case in relation to the timing of disclosure of recruitment to families should be used to ensure guidance in this area is as robust and as sensitive as possible.

Analysis



Analysis

Introduction: Interpreting Complexity with Care

This analysis sits at the intersection of facts, professional judgement, and lived experience. While it draws on multiple sources including records, policies, expert contributions, and family insights, it is not a simple retelling of events. It is a reflective, interpretative process aimed at understanding what happened, why it happened, and how we might learn from it.

Throughout this work, differing expert perspectives have emerged. These are not signs of error or failure, but reflections of the complexity inherent in the systems, decisions, and communication. Where disagreement exists, it is acknowledged. Where consensus was reached, it is noted. And where interpretation is necessary, these have been made transparently and with care.

This introduction recognises that no single narrative can fully represent every experience or every truth. Instead, this report offers a considered view rooted in values of compassion, fairness, and honesty. The intention is not to assign blame, but to create the conditions for learning, healing, and meaningful change.

Systems Engineering Initiative for Patient Safety (SEIPS). (The full analysis can be found in Appendix 9)

A SEIPS analysis was undertaken to examine how the work system contributed to missed opportunities for escalation and early intervention.

People: There were over 20 individuals who were involved in the care of Yusuf, with junior and middle-grade staff making complex decisions under time pressure and without consistent senior support, particularly over the weekend at SCH. Family concerns were not integrated into clinical decision-making. There were missed opportunities over the weekend for SCH to escalate Yusuf and human factors such as night working and weekend resourcing present.

Tasks: While observations were recorded, their interpretation and consideration was challenging when different organisations are involved in one person's care. Documentation was incomplete at SCH, particularly around differential diagnosis, escalation decisions, and visibility of consultant oversight.

Equipment, Tools & Technology: Pulse oximeters were not used at the GP surgery, infusion pumps and cannula management were not meeting the standards at SCH and clinical decision making documented effectively at SCH. Technology was different across

systems with paper records at SCH, different IT systems in each organisation and lack of continuity of care created between organisations.

Organisation: A culture of effective crisis response contrasted with limited proactive routine care.

This systems view confirms multiple interacting factors were present in Yusuf's within a complex eco-system of healthcare and Yusuf presentation was 'atypical' and therefore was not identified effectively with our traditional monitoring systems.

Thematic Review (with the benefit of hindsight)

This thematic review was developed through detailed analysis of expert reports, interviews and clinical records. They were further sense checked through Structured Judgement Reviews. Themes were identified by examining patterns and themes were identified such as lack of differential diagnosis, variability of respiratory assessment when a person is presenting with tonsillitis and identification that care at SCH occurred over the weekend and included night shifts. Similarly, the role of healthcare professionals as gatekeepers was identified through language, documentation, and behaviours that prioritised triage over advocacy and relational care which featured in all organisations.

The aim of this approach is to support compassionate, system-wide learning that strengthens future care and communication with families.

No	Themes	
1	**Trauma and death of a child (prolonged resuscitation)**	
2	**Professionals did not explore the respiratory symptoms described by Yusuf's mum in relation to 'breathing, snoring, breathlessness and 'jumping'**	
3	**Lack of Shared Decision Making**	
4	**Clinical Assessment of the Respiratory System**	Variables parameters measured including respiratory rate and pulse oximetry particularly in relation to tonsillitis

5	**Non Compliance with Evidence Based Practice at SCH**	1.Cannulation, Fixation and Care of Site 2.Medication Administration and Documentation Errors including IV antibiotics 3.Pump Management 4.IV Training 5. PEWS, Documentation and Escalation 6.Clinical Decision Making and Reviews
6	**Limited Differential Diagnosis**	Consistently not considered
7	**23 contacts, each with little continuity of care**	No single record
8	**The role of healthcare practitioners as gatekeepers and the impact on loss of advocacy**	Most roles were triage roles, GP, ambulance, ED and even the ward triaged for more severe symptoms and there was an absence of language that indicated wider advocacy
9	**Strong crisis management but less effective routine care**	When Yusuf became systemically unwell, positive clinical decisions were made but otherwise had a wait and see approach
10	**Weekend Resourcing at SCH**	This occurred over a weekend with admission on Friday evening and the identification of a possible worsening presentation on the early hours of 21st November.

1: Trauma	2-hour resuscitation and the death of a child

Understanding the Impact of Trauma

The events surrounding Yusuf included a prolonged two-hour resuscitation attempt, followed by the death of a child, a deeply traumatic experience for all involved. Trauma in such contexts is far-reaching, affecting individuals, teams, and systems in profound ways.

For those directly involved in the resuscitation, clinical staff, both doctors and nurses and other support personnel, the heightened physiological state driven by adrenaline can significantly alter perception, decision-making, and emotional regulation. While essential for urgent action, this altered state can obscure the emotional toll in the moment and complicate reflection and processing afterward. It is vital that we acknowledge how this biological response influences acute clinical judgement.

Beyond the immediate responders, the impact reverberates through those who knew and cared for Yusuf, his family, their GP practice, and wider professionals. The loss of a young life is a devastating event that shakes the foundations of those who provide care, particularly in tight-knit communities. For specialist services, who may encounter child deaths more frequently due to the nature of their roles, the cumulative weight of repeated trauma must be recognised.

2: Professionals did not explore the respiratory symptoms described by Yusuf's mum in relation to 'breathing, snoring, breathlessness and 'jumping'
3: Lack of Shared Decision Making

Failure to Acknowledge Parental Concerns

Yusuf's care highlights how the family's instinctive observations expressed repeatedly to healthcare providers across multiple settings went unheard or were downplayed and considers the consequences of this communication failure.

Evidence from research and national standards demonstrates that early caregiver concern (often termed *maternal instinct*) can be a valid predictor of serious illness, and that healthcare systems overly focused on measurable symptoms may miss subtle signs apparent to family members.

Discrepancies arose between the family's perception that Yusuf was severely unwell and the clinical narrative of a gradual deterioration.

We also note that there are documentation gaps where key family-reported symptoms were absent from medical records. This has an emotional toll on the family when their voice was not respected and relevant recent guidelines published reinforce the need to listen to families through shared decision making.

Unheard Parental Voice Across Multiple Healthcare Encounters

From primary care to hospital, the family's warnings were repeatedly not acknowledged. The child's mother sought help at every stage, her General Practitioner, an ambulance crew, Emergency Departments, and the paediatric ward, yet her observations were often minimised. In telephone consultations with NHS 111 and visits to the GP, she described symptoms which alarmed her: for example, she reported that her son was "sucking in his belly" with each breath and was difficult to rouse, "wouldn't open his eyes and was just fidgeting," and these were never explained.

These concerns (including abnormal breathing and episodes of the child "jumping" involuntarily) were often not present in the clinical record, TRFT correctly referred to "gasping for breath" in one instance but "snoring" in another, the ambulance described Yusuf as "waking up jumping"; while SCH used the term "snoring" but noted the absence of stridor.

It is understandable for parents to feel concerned when their child experiences heavy snoring or pauses in breathing during sleep. Snoring and sleep disturbance, including episodes of 'jumping', are common in young children with enlarged or inflamed tonsils due to tonsillitis.

Enlarged tonsils can temporarily block or narrow the airway during sleep, causing snoring, noisy breathing, and occasionally short pauses in breathing (apnoea) when a person relaxes which then leads to a sudden gasping for breath. While this can appear worrying, it is a frequently observed issue but requires explanation.

It's important to reassure parents that while this scenario can be distressing to witness, it's common, generally temporary, and typically resolves as the child's tonsils return to normal size and health.

However, the family's intuition was that "something isn't right" and this was not present in the documented history, contributing to a false sense of reassurance as the case progressed.

When Yusuf's condition worsened at home, the mother again voiced panic. In a WhatsApp message to a family member, she wrote: *"He keeps doing this every 5 mins?'*

This raw statement shows her fear that Yusuf was repeatedly having difficulty breathing. Although, as clinicians, we do not have access to her social media as part of our decision making, this reflects that fears were not adequately acknowledged by professionals.

On arrival at the Emergency Department (TRFT), the pattern continued. The mother's persistent concerns especially about her son's breathing and profound lethargy were not fully addressed. Multiple interactions e.g. 00:24, 00:42, 01:05, 01:37 and informal interactions mean staff were speaking to the family, however they are unable to respond to the families' repeated alarms about his breathing throughout the stay. These are not reflected substantively in any nursing or medical narrative albeit the term 'gasping for breath' reflected that the staff were aware of concerns. An independent witness concurred with this situation, independently asking for help for Yusuf but this failed to address the parents' concerns or feature in the notes.

Once again in the General Practice and ambulance, the family's experience was one of being devalued and not taken seriously by professionals was identified.

Staff responses can be understood as time limits and stretched resources create perfunctory and focused assessments on numeric triage scores and specific clinical signs. The child was given an initial assessment that yielded a low Paediatric Observation Priority Score (POPS), which contributed to the team's impression that there was no immediate high-risk issue leading to the decision to place Yusuf in the waiting room. Because the standard scoring did not flag a critical problem, her reports of "struggling to breathe" and extreme fatigue were insufficiently explored and addressed. It is noted that Yusuf was moved and monitored in a cubicle later which enabled monitoring.

There appears to be a "system-wide" tendency to invalidate symptoms that are genuinely concerning to a parent, often unintentionally. Regardless of the underlying need for treatment this leads to caregiver feeling, or actually, being labelled as over-anxious. This communication dichotomy leads to mistrust, even for conditions which are self-limiting and don't need further escalation.

The ED teams themselves state that all parents have anxiety when their children are ill which creates challenges in being able to manage their concerns effectively.

In desperation, the family step into advocacy roles even phoning the paediatric ward directly, begging to bypass the ED and have Yusuf admitted for urgent treatment, as their perception was that the GP had recommended IV antibiotics. The system cannot accommodate such a request and is unable to provide the valid and important explanations which underpin why an ED assessment was required. This led to further barriers, when the loss of trust in the hospital required the need to attend the specialist child hospital and was not the correct process for transporting Yusuf who needed oxygen.

Finally, during the hospital ward admission, the family remain convinced Yusuf was gravely ill, but again their views were downplayed. They observed that over the weekend Yusuf's

respiratory symptoms were worsening, pain was being experienced, and the cannula was leaking and yet staff did not escalate these findings.

The family were compelled to advocate repeatedly, only to be reassured without effective communication.

It is clear that across **all settings – primary care, pre-hospital, emergency, and inpatient** – the healthcare system failed to truly hear the family's voice.

Evidence for Maternal Instinct and Early Caregiver Concern

The mother's relentless worry was not mere anxiety, substantial evidence indicates that parental intuition can be an early and accurate indicator of serious deterioration. Research has long observed that parents are often the first to notice the subtle signs of a child's decline. In paediatric sepsis, for example, one prospective study found that a parent's "gut feeling" of serious illness had a remarkably high positive likelihood ratio (~16.4**)** for diagnosing severe infection like sepsis/meningitis[34]

In other words, when a parent was deeply concerned that "something is wrong," they are often correct. Correspondingly, the absence of parental concern had a strong negative likelihood ratio (0.23), meaning a child was unlikely to have life-threatening infection if the parents were not worried.

This underscores what many in paediatrics acknowledge anecdotally that maternal (or caregiver) instinct is a valuable red-flag symptom in its own right.

Leading healthcare guidelines formally recognise the importance of caregiver concern. The National Institute for Health and Care Excellence (NICE), in its guidelines for evaluating acutely ill children, advises clinicians to "pay particular attention to concerns expressed by parents, families or carers" about unusual changes in a child's behaviour or condition[35]. NICE's 2017 sepsis guidance explicitly includes parental concern as a high-risk criterion, on par with objective signs, for identifying possible sepsis[36].

The Royal College of Paediatrics and Child Health (RCPCH) likewise emphasises that parents are often the ones closest to the child and best positioned to notice early warning signs. RCPCH's recent statements around patient safety note that *"parents do know their children best,"* and a parent's insight that "he is just not right, I can't explain it" should be acted upon, not ignored[37].

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[34] pmc.ncbi.nlm.nih.gov

[35] **NICE Guideline NG197 on Shared Decision-Making** urge healthcare providers to work with patients and families in all decisions about care. It promotes effective communication, noting that clinicians should take into account the individual needs, preferences, and values of patients and consult with them and their families when exercising clinical judgment
nice.org.uk

[36] https://www.nice.org.uk/guidance/ng51

[37] safety.rcpch.ac.uk

Systemic Focus on Measurable Symptoms vs. Subtle Signs

This case highlights a misalignment between clinical assessment systems and the nuanced, non-verbal cues of serious illness that caregivers often observe. Modern clinical practice relies heavily on standardised tools and "track-and-trigger" systems to detect deterioration, for instance, Paediatric Early Warning Scores (PEWS) or Paediatric Observation Priority Scores (POPS) that assign points for abnormal heart rate, blood pressure, temperature, etc. These tools are invaluable for flagging obvious physiological changes, but they can fall short when a child's decline manifests in less quantifiable ways and appear that our processes over-ride parental concerns.

A tool that only counts objective measures might not trigger until the child's condition is critically advanced. These also provide thresholds for accessing care and create systems of patient flow that are unable to respond to the requests of parents.

The system is not designed to capture "something feels very wrong" as an input, and thus a gap opens between family and clinicians.

In paediatric practice, it is increasingly recognised that relying solely on quantitative metrics can lead to false reassurance. A child might still have "normal" observations while mounting a serious internal struggle, compensating such as maintaining blood pressure until crashing.

The misalignment meant that while the family were escalating their concerns, the healthcare team were not escalating care, and a fundamental disconnect between the family's alarm signal and the system's trigger threshold.

Divergent Perceptions: Mother's Certainty vs. Clinical Opinion

Throughout the illness, there was a stark disconnect between the family's perception of severity and the clinical narrative of Yusuf**.** The family believe Yusuf was *"always severely unwell"* from the very beginning of symptoms, whereas clinicians documented a more gradual deterioration, a child who was ill but with a minor self-limiting condition, then to an acute presentation, initially stabilising and appearing to get better but then later getting worse.

Both perspectives missed the chance for a collaborative understanding. The caregivers' *continuous* alarm was viewed with a degree of scepticism until objective evidence "caught up" (e.g. a collapse in vital signs or lab results confirming organ dysfunction). This impacts on both the family but also the staff.

Documentation Gaps: Missing Family Concerns in Records

Compounding the issue, key concerns voiced by the family were not documented in their voice in the official medical records, resulting in lost information and continuity gaps. Accurate, thorough documentation is vital in healthcare, not only for clinical handover but also because "if it's not documented, it didn't happen" in the eyes of subsequent providers.

In this case, the mother's reports of important symptoms and her level of worry were either omitted or downplayed in notes from multiple services. All records failed to include the mother's descriptions of her son's abnormal breathing patterns in her words (e.g. belly retracting with breaths), episodes of "struggling to breathe", and extreme sleepiness albeit they included other references to less acute presentation of breathing (not gasping, snoring or no respiratory distress) whereas the positive findings in relation to tonsillitis were included.

Nursing and medical notes include the child's observable clinical data (temperature, heart rate, throat examination findings, etc.) but omit statements like the mother's concern that "he can't sleep for a minute... I feel like something is very wrong."

Documentation is an acknowledgement of the caregiver's voice; excluding it sends a subtle message that those details were not considered important. According to national patient experience standards, healthcare professionals should ensure that patients' and families' concerns are heard, recorded, and shared as part of decision-making but currently this skill is absent from many of our records compounded by technology systems that create tick boxes not narrative. Shared decision-making has to include narrative from parents in order to demonstrate their understanding of the plan.

Impact on the Family

The experience of having concerns dismissed had a profound emotional and psychological impact on the family of Yusuf. From the early stages of the child's illness, they were worried for Yusuf while feeling unheard by those who were supposed to help. Her WhatsApp messages portray a parent who is exhausted and fearful. *"I have zero energy, I am sooo drained out,"* she wrote *"He can't sleep for a min even daytime… I feel like I'm gonna drop."*

This candid message illustrates the physical exhaustion and anxiety endured as Yusuf remained ill without improvement. She describes holding her son upright all night so he could breathe and sleep, to the point of utter fatigue. Yet, despite her desperation, when she sought help, she often felt dismissed or even judged as overly anxious.

The family did everything in their power: they returned to the GP twice, they called 111 and 999, they went to ED twice, they called The Ward, and eventually were admitted. At each stage the organisation responded according to protocol and would be considered as being correct in their management.

Such experiences can leave families with deep emotions: guilt (wondering if they should have done even more or pushed harder), loss of trust in healthcare, and psychological trauma from feeling unheard during a crisis.

Impact on Clinical Staff

The emotional toll of incidents such as this extends significantly beyond the family, profoundly affecting clinical staff as well. Healthcare professionals often enter their roles driven by a commitment to provide compassionate and effective care. When systemic

barriers, miscommunications, or missed cues result in negative outcomes, clinicians may experience moral distress, feelings of guilt, and profound regret, questioning their own clinical judgement and decision-making. Such cases can erode confidence, increase stress, and contribute to burnout, compassion fatigue, and even departure from the profession[38].

Evidence shows that when systems fail to adequately integrate caregiver concerns and intuitive observations, clinical teams themselves suffer emotional consequences, including anxiety about future interactions, fear of repeated incidents, and difficulty maintaining trustful relationships with families. Addressing these systemic communication gaps is therefore critical not only for patient and family wellbeing but also for supporting the resilience and emotional health of healthcare staff, ensuring they feel empowered to act on parental instincts without fear of deviation from clinical protocols.

In practical terms, this means clinicians should view parents as partners, not as bystanders or obstacles. The RCPCH and other bodies have supported initiatives to ensure families can raise concerns. Notably, there are calls to implement **"**Martha's Rule" across NHS hospitals and gives patients, parents or carers the *right to easily request a second opinion or rapid review* by a senior clinician if they feel their concerns are not being heeded during an inpatient stay.

A culture change is needed whereby maternal instincts and caregiver observations are not seen as secondary to "hard data," but rather as different forms of evidence that deserve attention. As one parent eloquently implored healthcare providers: *"Please listen to us when we say something is not right… we are simply trying to give a voice to our children as they don't have one of their own[39]."*

4: Clinical Assessment of the Respiratory System	Variables parameters measured including respiratory rate and pulse oximetry especially in relation to tonsillitis.
6: Limited Differential Diagnosis	Consistently not considered

[38] Annina Seiler, Aimee Milliken, Richard E. Leiter, David Blum, George M. Slavich, The Psychoneuroimmunological Model of Moral Distress and Health in Healthcare Workers: Toward Individual and System-Level Solutions Comprehensive Psychoneuroendocrinology,Volume 17 2024,
[39] DFTB (Don't Forget the Bubbles) Sepsis 2020 – Commentary on NICE paediatric sepsis guidance dontforgetthebubbles.com

Illustrative Respiratory Observations Highlighting Variation Across Organisations

This is not a complete record and some organisations completed additional assessments.

Assessment	RR	HR	Pulse Oximetry	Chest Examination	Increased Work of Breathing	Capillary Refill
GP (first visit)	No	No	No	Yes - clear	Stated none	<2 secs
ED Rotherham	22	88-113	98-99%	Yes - clear	Stated none	<2 secs
GP (second visit)	No	122	No	Yes - clear	Stated none	No
Ambulance Crew	32	160	91% on air	Yes- clear	Stated none	No
ED SCH triage 18th	38	100	89% on air	Bilateral wheeze	Tracheal Tug	<2 secs
Senior Registrar Review (23:30 18th)	28	100	99% on 1 litre	Yes - clear	No comment	No
ENT Review (9:00 19th)	PEWs 2	PEWs 2	97% on 4 litres	No comment	No Stridor	No
Paediatric Team Review (12:15, 19th)	28	98-119	98% 4 litres	Transmitted sounds	Occasionally snoring/Mild Intercostal	Not recorded
Medical Team Review (12:15 20th)	28	86	100% 4 litres	Transmitted sounds and mild S/C recession	Snoring is improving	<2secs
Initial morning review (08.15 21st)	32	112	97% 5 litres	Decreased air entry bilaterally	Chest tightness hurts to breaths	Not recorded

Respiratory Assessment

Variability in respiratory assessments was seen across the chronology, in part driven by the primary diagnosis, tonsillitis and partially through the scoring tools different organisations used. In the UK, studies have highlighted inconsistencies in clinical practices related to respiratory care, underscoring the need for standardised assessment protocols and consider how technology can support assessment. With suspected severe infections, Yusuf should be assessed with full physiological parameters, including respiratory rate, heart rate, capillary refill, and pulse oximetry.

Observations of Variability:

Respiratory Rate was missing in both GP visits. It was consistently 22 in the Emergency Department in Rotherham and was elevated in the Ambulance and throughout the stay in SCH elevated on occasions.

Heart Rate was measured consistently with the exception of the initial GP visit.

Oxygen Saturations were not recorded by the GP, but were part of the assessment whilst at ED in TRFT, continued to be undertaken in the ambulance and were an important parameter which Yusuf was being monitored through at SCH.

Chest Sounds were recorded across all the clinical entries with mostly “clear” except for bilateral wheeze at ED triage in SCH but then improved with treatment. Transmitted sounds were a new feature on the morning of the 20th. In healthy lungs, sound is muffled because air-filled lungs scatter sound waves. If lungs become filled with fluid, pus, or collapse (making them more solid), sound is transmitted more directly and clearly hence "transmitted sounds."

Signs of the presence or absence of respiratory distress were recorded consistently across the chronology and formed a critical element of the assessment.

Capillary Refill Time was not recorded in every interaction although formed part of triage.

Inconsistency of Respiratory Assessment is a Common Finding

The omission of respiratory rate measurements in initial assessments can hinder early detection of respiratory distress. The British Journal of Nursing stresses the importance of respiratory rate monitoring, noting discrepancies in its assessment and documentation among healthcare professionals[40].

Inconsistent assessments can postpone the identification of respiratory conditions, leading to delays in initiating appropriate therapies and early warning systems, which rely on accurate and consistent vital sign measurements, are essential in predicting and preventing patient deterioration.

Differential Diagnosis

Throughout Yusuf’s journey, tonsillitis was consistently identified as the primary diagnosis. While this remains the primary likely diagnosis initially, the sustained focus on a single explanation led to diagnostic anchoring and a failure to consider broader differentials. Key indicators such as variable presenting features and declining oxygen saturations were not adequately explored in relation to alternative or co-existing conditions, albeit asthma and reactive airways disease was considered at SCH. This diagnostic bias limited critical

[40] Bracey, P., McCann, T. and Jackson, M., 2019. The importance of respiratory rate monitoring. British Journal of Nursing, 28(5), pp.294–298. Available at: https://www.britishjournalofnursing.com/content/clinical/the-importance-of-respiratory-rate-monitoring [Accessed 1 Apr. 2025].

thinking and contributed to missed opportunities to identify a changing clinical picture. Even those organisations that presented early in Yusuf journey so the symptoms present at that time did not give any indication of what was to happen at the weekend, should consider the importance of being open-minded to alternative diagnosis and consider differential diagnosis proactively as part of organisational learning.

Bias[41]

How our health practitioners make decisions is important to understand as this creates insight into errors that might form particularly when Yusuf and his symptoms were not responsive to treatment and featured as 'atypical' pneumonia.

The repeated attribution of the patient's condition to tonsillitis, despite evolving clinical features, suggests an anchoring bias where the initial diagnosis unduly influenced subsequent clinical assessments. Once tonsillitis was established as the working diagnosis, alternative explanations were not actively pursued, even as objective signs of deterioration (falling oxygen saturations) emerged.

Confirmation bias may also have been present, where clinicians unconsciously selected and interpreted clinical findings in a way that supported the initial diagnosis, rather than challenging it. For example, chest auscultation was repeatedly documented, while signs of respiratory symptoms such as decreasing oxygen saturations and transmitted sounds were underplayed.

Clinicians often rely on pattern recognition as part of their clinical judgement especially when there are time pressures and roles with high cognitive load. In this case, the lack of escalation and limited differential consideration from Friday 18th November suggest that such biases went unchallenged across multiple points of care, contributing to diagnostic delay and the under-recognition of a deteriorating clinical picture.

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5: Non Compliance with Evidence Based Practice at SCH	1.Cannulation, Fixation and Care of site 2.Medication Administration and Documentation Errors including IV 3.Pump Management 4.IV Training 5. PEWS, documentation and escalation 6.Clinical Decision Making and Reviews

Non Compliance with Evidence Based Practice at SCH

Vascular Access and Intravenous Therapy Review including Pump Management (See Appendix 5).

The management and documentation of intravenous (IV) therapy in this case demonstrated multiple deviations from national standards and best practice. Documentation of cannula insertions, site changes, and fixation methods was incomplete and failed to meet Royal College of Nursing (RCN) Infusion Therapy Standards (2016). In particular, the use of wrap-around bandaging obscured site visibility, limiting effective monitoring.

Although VIP (Visual Infusion Phlebitis) scores were recorded at isolated time points, these were not performed consistently particularly during periods of continuous infusion and hourly site and pump pressure checks were not documented, as required by local and national guidelines. Trust guidelines were outdated (last reviewed in 2015) and lacked reference to Aseptic Non-Touch Technique (ANTT), contributing to variation in practice.

Family photographs were relied upon to establish timelines that were absent from clinical records.

These issues may have resulted in compromised drug delivery, reduced treatment efficacy, and increased infection risk.

IV Therapy Training & Competency (See Appendix 5)

There was no Trust-wide standardised approach to IV therapy training, and no designated lead for vascular access education. IV therapy, a core nursing skill, was incorrectly treated as an extended role. Existing competency booklets focused on medicines management but failed to cover essential IV therapy competencies such as site assessment, flushing, administration, and care of vascular access devices.

Medication Prescribing and Administration Errors (See Appendix 5)

Medication errors and documentation discrepancies were identified, including deviations from prescribed timings or doses for metronidazole and dexamethasone. There was

inconsistent or absent documentation regarding delayed or omitted doses, and unclear prescribing instructions particularly for Oromorph which led to confusion between scheduled and as-needed administration. Errors included unprescribed additional dose of dexamethasone and omissions without medical review or documented rationale in relation to any altered administration time for IV antibiotics.

Paediatric Early Warning Score Escalation and Documentation (See Appendix 5)

It was considered by the authors of this report that there were significant documentation gaps in response to elevated Paediatric Early Warning Scores (PEWS). In instances, including scores of 7, 6, and 4, there was no documented evidence of escalation to senior nursing or medical staff and it was considered by the organisation that actions that had occurred such as replacing oxygen which then led to improvement were robust responses. This led to missed opportunities for medical oversight. Vital signs documentation on occasion omitted key parameters such as blood pressure and capillary refill time, alongside parental concerns and pain compromising the accuracy of PEWS calculations.

Clinical Decision Making and Reviews (See Appendix 4 and Appendix 5).

Concerns were identified regarding clinical decision-making and adherence to medical review standards, discrepancies between nursing and medical documentation particularly regarding key clinical observations were not reconciled, and contradictory presenting signs and diagnoses were not adequately reviewed or escalated. These gaps suggest a lack of coordinated clinical oversight and a failure to respond appropriately to indicators requiring senior input.

7: 23 contacts, each with little continuity of care	No single record
10: Weekend Resourcing at SCH	The incident occurred over the weekend, with admission on Friday evening and the identification of the worsening presentation on Monday morning.

Continuity of Care, Fragmented Records, and Weekend Resourcing

Yusuf was overseen by more than 30 clinical contacts with at least 23 different professionals across multiple healthcare organisations. These contacts occurred over an eight-day period, including a weekend, yet there is no ability in our current systems to create a single, continuous plan of care or a centralised record accessible to all

professionals involved. Records were kept on both computer systems but also in SCH included paper records, which created barriers to share essential clinical information. The use of multiple systems and formats further impaired shared understanding of Yusuf's clinical status, progression, and decision-making and is a known national theme in many patient safety investigations.

Weekend staffing and resourcing added to the complexity at SCH. Although clinical contacts continued over the weekend, the absence of consistent senior medical review, possibly delayed diagnostic decision-making, and a lack of clearly documented escalation decisions reflect the system-wide challenges associated with care.

There are three handover points each day of the weekend, with a named medical consultant over the weekend with continuous oversight. This was not clearly visible in the documentation as they are remote from the patient and recorded in paper records. Two teams were reviewing Yusuf and his care which further contributed to possible fragmented decision-making. From the medical record, no single individual appeared to take ownership of the overall care plan, and continuity was lost between reviews. This made it difficult to trace clinical reasoning, especially when new symptoms emerged, or prior assumptions needed to be challenged.

8: The role of healthcare practitioners as gatekeepers and the impact on loss of advocacy and there was an absence of language that indicated wider advocacy
9: Strong crisis management but less effective routine care

The Shift from Advocacy to Gatekeeping: Compassion Fatigue in Healthcare Systems

A recurring theme in this investigation was the prevalence of triage-driven interactions across the care for Yusuf. While triage is an essential function in emergency contexts, it has become a dominant mode of engagement even within inpatient settings and routine ward-based care. Staff described how decisions, whether to escalate, to refer, to admit, or to reassure were frequently framed in triage terms, with thresholds shifting depending on time of day, day of the week, and available resources. It is important to acknowledge that in every narrative, there were adequate resources available however the unconscious knowledge of stretched services was revealed when the conversations were widened to different situations.

This shift, while often necessary in resource-constrained environments, appears to have displaced a key professional role: advocacy.

Advocacy, for Yusuf, for their family, for colleagues, and even for the service itself was not present. Healthcare professionals are not trained to be gatekeepers; they are trained to undertake a specific role, whether as a doctor, nurse or wider member of the team. Yet the constant negotiation between clinical judgement and resource availability has possibly over time, eroded this identity.

This erosion is not benign. It contributes to moral distress, the discomfort or pain experienced when professionals know what care is needed but feel unable to deliver it. Moral distress, over time, contributes to compassion fatigue, a state of emotional and physical exhaustion that can diminish a professional's capacity to empathise or advocate effectively[42].

Compounding this issue is the presence of a dual standard of care observed during the review. When Yusuf was identified as being acutely unwell, the system responded with high-quality, coordinated, and timely intervention, demonstrating the capability to mobilise effectively in crisis. However, the care provided, particularly over the weekend at SCH, appeared more fragmented and reactive and lacked advocacy. This contrast highlights a structural gap, while escalation pathways exist for overt deterioration, there are limited safeguards to detect or recover from missed opportunities to escalate. In the absence of proactive safety nets or real-time oversight mechanisms, signs of deterioration that do not reach critical thresholds may go unchallenged. This is not a reflection on the individual nurses involved, but rather a system-level issue requiring consideration of how routine care is supported, monitored, and escalated outside of crisis response.

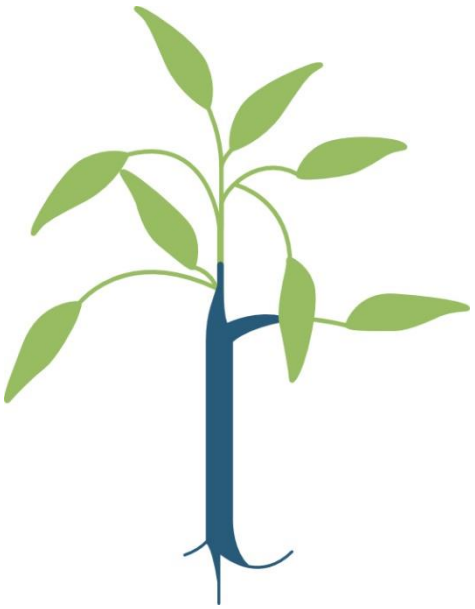
Yusuf’s family were trying to pre-empt deterioration but found themselves in conflict with services. They were often not deemed "sick enough" to activate a full system response. Meanwhile, services were wary of becoming overwhelmed by families who were "worried but well." This dynamic created a culture, where Yusuf’s family felt they had to fight for access, and staff felt they had to possibly, albeit unconsciously, defend the system.

This investigation invites us to consider whether our systems under the pressure of sustained resource constraint have unconsciously deprioritised advocacy in favour of risk management. If we ask professionals to continually triage without addressing the structural gaps that lead to unmet need, we risk normalising a culture of gatekeeping. In such a culture, compassion fatigue is not an individual failing, but a systemic symptom.

Rebalancing our systems will require us to reconnect with advocacy, not just in moments of crisis, but as a core value embedded in everyday care. It also means recognising that effective advocacy is not possible without psychological safety, time, and trust.

[42] https://www.bma.org.uk/bma-media-centre/bma-research-finds-doctors-are-suffering-emotional-and-psychological-distress

Summary of Findings, Areas for Improvement and Safety Actions



Summary of Findings, Areas for Improvement and Safety Actions

Introduction to Nurture Safety Bridging Statements

A Safety Bridging Statement is a tool used within independent investigations or reviews to highlight a specific area of concern related to safety, without prescribing a fixed solution. Instead, it provides a clear, evidence-informed summary of the issue, allowing the receiving organisation the autonomy to develop its own safety action in response.

The purpose of a Safety Bridging Statement is to support the organisation in understanding the nature and potential impact of the concern, while empowering them to design a response that is specific, measurable, and proportionate to their own context, resources, and operational framework. It ensures that learning is transferred constructively, while respecting organisational accountability and the need for tailored safety improvements.

The following reflective questions have been developed in response to a complex and a systems-based approach to investigation. Rather than relying solely on procedural recommendations, these acknowledge that meaningful learning and improvement often arise not from definitive answers, but from thoughtful, shared questioning.

These statements are designed to do more than instruct, they invite reflection.

Organisations are encouraged to use these questions as starting points for internal enquiry, reflection, and conversation. Whether through multidisciplinary forums, reflective practice sessions, or governance meetings, teams can use them to co-design local safety actions and recommendations that are grounded in lived experience and context;

- How might care change if we treated a caregiver's intuition not as an adjunct, but as a legitimate and vital form of evidence? What becomes possible when the instinct of a mother is given the same attention as a monitor reading?

- How can our systems which were built to triage risk, uphold advocacy as an act of care, even when resources are limited?

- We recommend that systems of governance move beyond procedural assurance and incorporate reflective, trauma-informed practices that acknowledge the emotional labour of care and moral injury. This includes:
    - Recognising trauma as a legitimate influence on decision-making, behaviour, and team dynamics.
    - Embedding reflective space within governance structures, not outside of them.
    - Asking not just what went wrong, but what was the emotional cost and how do we learn and support each other?

In addition, Experts have written recommendations in their reports seen in the appendices. SMART recommendations below summarise these actions. Many of these were included as part of organisational action plans so may have already been achieved.

1. General Recommendations *(Applicable Across All Areas)*

Differential Diagnosis

- **Specific & Reasoned:** Implement structured reflective practice within supervision to systematically consider differential diagnoses, explicitly addressing cognitive biases.
- **Measurable & Achievable:** Develop audit criteria for medical records to verify inclusion of differential diagnosis by December 2025.
- **Realistic & Effective:** Identify whether the audit has positively impacted on the management of patients by considering how you can measure identification of the outliers, those who have not responded to initial treatment and therefore benefited from an alternative diagnosis.

Embedding Caregiver Concerns

- **Specific and Reasoned:** Embed consultation skills addressing caregiver concerns within existing departmental education and simulation programmes focused on managing the acutely unwell child.
- **Measurable and Achievable**: Ensure 100% of relevant local training programmes including simulations include clearly defined learning outcomes related to caregiver communication skills and are completed by December 2026.
- **Realistic and Effective:** Enhance clinicians' skills in managing caregiver concerns improving overall patient and caregiver experience in acute presentations.

Integrate this objective within existing educational frameworks, avoiding additional burdens by leveraging current simulation and educational resources.

2. THE ROTHERHAM NHS FOUNDATION TRUST (TRFT) RECOMMENDATIONS

- **Specific & Achievable:** Introduce structured documentation prompts specifically designed to consistently capture and address parental concerns during clinical and nursing assessments. Implement by June 2026.
- **Measurable & Timebound:** Audit patient records quarterly from June 2026 to confirm structured prompts are routinely completed and actioned effectively.

3. YORKSHIRE AMBULANCE SERVICE (YAS) RECOMMENDATIONS

Work Pressure Impact including staff downtime & break management.

- **Specific and Achievable:** Conduct a comprehensive review of current workloads for ambulance crews including staff downtime and breaks.
- **Measurable & Timebound:** Complete review and provide a report with actionable recommendations by December 2025.

Cultural Competence, Safety and Civility

- **Specific and Achievable:** Implement into your mandatory training programmes Cultural Competence and Civility Saves Lives principles, specifically designed to equip ambulance crews with skills to recognise and respond effectively to diverse cultural needs, while understanding how professional attitudes and behaviours significantly influence patient experience, safety, and include unbiased handovers.
- **Measurable & Timebound:** Evaluate training impact annually through patient feedback surveys and complaint's themes, beginning December 2025.

Patient Choice Clarification

- **Specific and Achievable:** Develop clear guidelines and patient materials for ambulance staff to communicate effectively with patients regarding their rights to choose care options versus emergency medical priorities.
- **Measurable & Timebound:** Publication of patient materials and their usage reviewed in December 2026.

4. SHEFFIELD CHILDREN'S HOSPITAL (SCH) RECOMMENDATIONS

The review acknowledges that Martha's Rule was not in place when the incident occurred but consider if this had been adopted along with the National PEWS chart that the voice of mum would have been acted on. The Trust's leadership as a Phase 1 site for the implementation of Martha's Rule and the proactive development of processes such as the Parent and Carer Escalation (PaCE) system, daily wellness checks, and digital ward flags are building on a strong foundation to embed the principles of Martha's Rule across paediatric services, ensuring that parental concerns are consistently recognised, documented, and responded to as a valued part of clinical assessment and safety escalation. This creates an opportunity to become a flagship site, modelling best practice for the meaningful inclusion of family voice in paediatric safety and escalation systems nationally.

Comprehensive Vascular Access Guidelines

- **Specific and Achievable:** Undertake comprehensive review and revision of all vascular access and intravenous therapy guidelines, integrating ANTT standards and Vessel Health and Preservation guidance (2020) for clinical decision-making.
- **Measurable & Timebound:** Guidelines revised and disseminated by September 2025.

Standardised IV Therapy Training

- **Specific and Achievable:** Identify intravenous therapy and vascular access training building on the guidelines across the trust to enhance governance and clinical safety.
- **Measurable & Timebound:** Standardised training curriculum implemented and evaluated annually, commencing January 2026.

Clinical Practice Monitoring (Intravenous Therapy)

- **Specific and Achievable:** Adopt Device-Related Infection Prevention Practices (DRIPP) audits as regular practice to continually monitor and improve intravenous therapy and vascular access care standards.
- **Measurable & Timebound:** Quarterly auditing implemented from June 2025, with results integrated into continuous improvement actions.

Cannula Insertion & Fixation

- **Specific and Achievable:** Create and adopt a robust, evidence-based cannula/vascular access insertion guideline, clearly defining ANTT practices, recommended dressing techniques and escalation procedures for difficult insertions.
- **Measurable & Timebound:** Full guideline implementation with staff training completed and audited for compliance by December 2025.

Medicines Management Policy Review

- **Specific and Achievable:** Revise Medicines Management Policy to explicitly acknowledge intravenous therapy as an integral nursing practice, detailing mandatory training and competency assessment requirements across multidisciplinary teams.
- **Measurable & Timebound:** Implementation across trust with measurable compliance by December 2025, evidenced through training audits.

Prescription Chart Review

- **Specified & Achievable:** Redesign prescription charts for clarity, ease of prescribing and administration, ensuring compatibility with best practice and consideration of double signature administration requirements. Evaluate feasibility of transitioning to electronic prescribing systems.
- **Measurable & Timebound:** Revised charts implemented and evaluated through staff and prescriber feedback by June 2026, with clear decision timeline for electronic prescribing adoption.

PEWS Training and Escalation Pathways

- **Specific & Achievable:** Roll out trust-wide Paediatric Early Warning Score (PEWS) training and ensure clear dissemination and regular reinforcement of escalation pathways, clarifying triggers and responsibility roles.
- **Measurable & Timebound:** Training completed for all relevant multidisciplinary staff by December 2025, followed by annual refresher sessions and audit of compliance and effectiveness.

Weekend Medical Consultant Visibility

- **Specific & Achievable:** Establish visible consultant-led oversight for every child for acute wards for handovers and recorded in the medical record.
- **Measurable & Timebound:** This should be achieved by September 2025 and demonstrated through rota compliance.

5. EXPERT-LEVEL RECOMMENDATIONS

- NIHR commissioned research to quantify the extent to which caregivers feel their concerns have not been addressed following a consultation.
- NIHR commissioned research on the association between tonsillitis and secondary infections (including Group A Strep) which may help with designing future guidance on children presenting with tonsillitis.
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6. FAMILY-REQUESTED RECOMMENDATIONS

- To ensure families are informed that when their children are on ventilators, they may still be able to hear, and should be encouraged to talk to and interact with them.
- To ensure that any items such as clothing or equipment can be saved so families can keep as memories when a child dies.

7. **NATIONAL RECOMMENDATIONS** *(which are not considered SMART but intended to inform wider system improvement):*

The family and the review team have identified areas where system-level reflection and long-term planning may support improved outcomes for children and families across the country. These recommendations are not prescriptive, but intended to inform national discussions on workforce, transparency, and family involvement:

Sustainable Consultant Oversight Models

Explore the development of a national workforce plan to support sustainable consultant oversight across seven-day services, particularly in paediatrics. This should include consideration of realistic models for weekend medical review that balance patient safety, continuity of care, and workforce wellbeing, acknowledging the pressures during high-demand periods such as winter.

Parental Access to Medical Records

Consider national guidance on enabling parents to have appropriate visibility of their child's medical records during admission, potentially learning from models such as maternity-held notes, to support shared understanding of care plans and promote collaborative decision-making.

Review of Paper-Based Medical Records

Undertake a national review of the continued use of paper-based records in paediatric settings, recognising the impact this can have on continuity and safety.

Appendices

1. Full Chronology
2. CCTV Chronology
3. Evidence Log
4. Expert Report: Doctor
5. Expert Report: Nursing
6. Expert Report: Ambulance
7. Expert Report: Workforce
8. Interviews and Structured Judgement Reviews
9. SEIPS
10. Workforce – Review 2005-2025
11. References
12. SCH Paediatric and Perinatal Pathology Workforce
13. Number of Clinical contacts
14. SCH Reflective Statement re Post-Mortem
15. Scanned Clinical Records
16. Terms of Reference
17. Addendum: Overnight Clinical Oversight and Escalation of 20th–21st November 22 Timeline

Glossary

- **Afebrile** – Not having a fever; normal body temperature.
- **Analgesia** – Pain relief medicine.
- **Antibiotics (IV antibiotics)** – Medicines given into a vein (intravenously) to treat infections caused by bacteria.
- **Apyrexial** – Having no fever.
- **Asthma** – A common condition causing breathing difficulties, coughing, and wheezing.
- **Atypical pneumonia** – A lung infection caused by uncommon germs or viruses.
- **BD** – Twice daily (bis in die).
- **Bilateral cervical glands** – Swollen glands on both sides of the neck.
- **Bilateral exudate** – White or yellow fluid on both tonsils, often seen in throat infections.
- **Bilateral wheeze** – Whistling sound from both lungs, often due to narrowed airways.
- **Blood gas** – A test measuring oxygen and other gases in blood.
- **BNF** – British National Formulary; a medical reference for medicines.
- **BNFC** – British National Formulary for Children.
- **Bronchodilator therapy** – Medicine given to widen airways and ease breathing.
- **BSP (Bowel Sounds Present)** – Normal gut sounds heard when examining the abdomen.
- **Cannula/Cannulation** – A small tube inserted into a vein to give medicines or fluids.
- **Capillary refill time** – A test checking blood flow, pressing skin and seeing how fast colour returns.
- **Care Quality Commission (CQC)** – The independent regulator that checks quality and safety in health services.
- **CareFlow Vitals** – A digital system hospitals use to record patients' vital signs.
- **Causative agent** – Germ or virus causing illness.
- **Cefuroxime** – An antibiotic medicine used to treat infections.
- **Chest sounds** – Sounds from lungs heard through a stethoscope, used to assess breathing.
- **Chest X-ray** – An imaging test to see inside the lungs and chest.
- **Clinical assessments** – Medical checks by doctors or nurses to see how unwell someone is.
- **Concordance** – Agreement or cooperation, usually about taking medicines correctly.
- **Continuity of care** – Consistent and coordinated healthcare from the same or closely connected medical staff.
- **Coroner** – An official who investigates unexpected or unexplained deaths.

- **CCTV** – Closed Circuit Television.
- **CPR (Cardiopulmonary Resuscitation)** – Emergency treatment used when a person's heart or breathing stops.
- **CRP** – C-Reactive Protein.
- **Death certification** – Official document recording the cause and details of a death.
- **Decompensated** – When the body can no longer cope with illness, causing severe symptoms.
- **Dehydration** – Lack of water in the body, often due to illness.
- **Dexamethasone** – A steroid medicine reducing swelling and inflammation.
- **Diagnostic errors** – Mistakes or delays in identifying what illness someone has.
- **Differential diagnosis** – Possible different illnesses being considered by medical staff.
- **ED** – Emergency Department.
- **ENT** – Ear, Nose and Throat specialist doctor.
- **Erythromycin** – An antibiotic medicine used when someone can't take penicillin.
- **ETT (Endotracheal Tube)** – A tube placed through the mouth into the windpipe to help someone breathe.
- **F2F (Face-to-Face)** – Seeing patients in person.
- **GP** – General Practitioner.
- **Glucocorticoids** – Steroid medicines used to reduce inflammation.
- **HS I + II + 0** – Normal heart sounds heard during examination.
- **Hypoxaemia/Hypoxia** – Low levels of oxygen in the blood.
- **Iatrogenic** – Harm or illness caused accidentally by medical treatment.
- **ICB** – Integrated Care Board.
- **IEI** – Inborn Errors of Immunity.
- **IPSI**– Independent Patient Safety Investigation.
- **IV**– Intravenous.
- **Initial Acuity: Low Acuity** – Initial assessment suggesting someone isn't seriously ill at first.
- **Intravenous Therapy (IV Therapy)** – Treatment delivered directly into a vein.
- **JRCALC** – Joint Royal Colleges Ambulance Liaison Committee.
- **Kernig's sign negative** – A test indicating a patient likely does not have meningitis.
- **Laboratory testing** – Medical tests analysing blood, urine, or other samples.
- **Leukemoid reaction** – A very high white blood cell count caused by infection or stress.
- **LOC (Loss of Consciousness)** – Fainting or becoming unconscious.
- **Locum** – Temporary doctor covering shifts or short-term vacancies.
- **Martha's Rule** – A patient safety rule allowing patients or families to request a second medical opinion if worried.
- **Medical Examiner** – Doctor reviewing deaths to ensure accuracy and safety.

- **Metronidazole** – An antibiotic treating certain bacterial infections.
- **Monteleukast, Clenil, Salbutamol** – Medicines commonly used to treat asthma.
- **NAD (Nothing Abnormal Detected)** – No medical concerns found during a physical check.
- **National Institute for Health and Care Excellence (NICE)** – Organisation giving national guidance on best medical practice.
- **NCMD** – National Child Mortality Database.
- **Nebuliser** – Device turning liquid medicine into mist for inhalation.
- **NHSE** – National Health Service England.
- **NIHR**– National Institute for Health and Care Research.
- **NPSIIT**– NHSE National Patient Safety Independent Investigation Team.
- **Oromorph** – Liquid morphine, a strong painkiller.
- **Otoscope** – Instrument used by doctors to look inside ears.
- **Oxygen saturation (sats)** – Measure of how much oxygen is carried in the blood.
- **PACE**–Paediatric Assessment & Clinical Escalation.
- **Paediatric Early Warning Scores (PEWS)** – A scoring system helping medical staff quickly identify seriously ill children.
- **Paediatric pathology** – Medical specialty studying diseases in children.
- **Pathogens** – Germs or viruses causing illness.
- **PCR (Polymerase Chain Reaction)** – Test detecting specific germs, often viruses, from samples.
- **Phenoxymethylpenicillin** – Common antibiotic used to treat throat infections.
- **Pneumonia** – Lung infection causing breathing difficulties.
- **POPs (Paediatric Observation Priority Score)** – Another early warning system for assessing sick children.
- **Post-mortem** – Examination after death to understand cause of death.
- **PSIRF** – Patient Safety Incident Response Framework.
- **Pulse oximeter** – Device measuring oxygen in blood by attaching to a finger or toe.
- **Radiological evidence** – X-rays or scans showing signs of illness.
- **RCPCH**–Royal College of Paediatrics and Child Health.
- **Reactive airways disease** – General term for breathing difficulty like asthma.
- **Resuscitation** – Emergency procedures to save lives, such as CPR.
- **Retrospective consent** – Consent obtained after treatment or tests are performed, usually in urgent cases.
- **RR (Respiratory rate)** – Number of breaths someone takes per minute.
- **SCH** – Sheffield Children's NHS Foundation Trust.
- **SEIPS analysis** – Method used to investigate healthcare incidents, considering systems, environment, and people.
- **Sepsis** – Life-threatening condition where the body reacts severely to an infection.
- **Sensitivity and resistance patterns** – Laboratory tests showing which antibiotics work against specific germs.

- **SMART**– Specific, Measurable, Achievable, Relevant, Time-bound.
- **Stress hyperglycaemia response** – Temporary increase in blood sugar due to stress or illness.
- **ST4 / SpRs (Specialist Registrars)** – Senior doctors in training.
- **Suprasternal recession** – Visible sucking in of the chest when breathing, indicating respiratory distress.
- **Suction** – Removing fluid or mucus from airways using special equipment.
- **Tachycardia** – Fast heart rate.
- **Tachypnoea** – Fast breathing rate.
- **Tonsillitis** – Infection causing inflammation of tonsils.
- **Transmitted sounds** – Lung or breathing sounds heard through a stethoscope that originate elsewhere.
- **TRFT** – The Rotherham NHS Foundation Trust.
- **Type 1 respiratory failure** – Severe condition where the lungs can't supply enough oxygen to the blood.
- **UECC** – Urgent Emergency Care Centre.
- **UNCRC**– United Nations Convention on the Rights of the Child.
- **Ventilator** – Machine helping patients breathe.
- **Viral infection** – Infection caused by a virus rather than bacteria.
- **VIP scoring/site inspections** – Checks for signs of infection or problems at the site of a cannula.
- **Vital signs** – Basic body checks including heart rate, breathing, blood pressure, temperature, and oxygen levels.
- **YAS**– Yorkshire Ambulance Service NHS Trust.