

An independent investigation into the care and treatment of Yusuf

York Road Surgery

Yorkshire Ambulance Service NHS Trust

The Rotherham NHS Foundation Trust

Sheffield Children's NHS Foundation Trust

September 2023

FINAL ABRIDGED REPORT (PUBLICATION)

Report Advisory Notice

This report deals with difficult subjects relating to care and treatment of a child. We have made efforts to write our report in a way which is not overly descriptive and limits the use of third-party and non-relevant personal information. However, there are instances where information is necessary, for example, where an opinion has been quoted or a specific act has been documented and this is relevant to the case. We do advise caution in those who may be triggered by reading information which might be sometimes distressing, particularly, that they are helped to read this report in a safe and supported way.

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Final Abridged Report: September 2023

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Our Final Report has been written in line with the terms of reference as agreed with NHS England dated 24 January 2023. This is a limited scope review and has been drafted for the purposes as set out in those terms of reference alone and is not to be relied upon for any other purpose.

Events which may occur outside of the timescale of this review will render our report out-of-date. Our report has not been written in line with any UK or other (overseas) auditing standards, we have not verified or otherwise audited the information we have received for the purposes of this review and therefore cannot attest to the reliability or accuracy of that data or information.

This is a confidential report and is for the sole attention of the project sponsor. No other party may place any reliability whatsoever on this report as this report has not been written for their contractual purposes. This report does not contain any legally binding opinion and further advice might be required to establish a legal basis.

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Part 1 – Summary

Background

- 1.1 On Wednesday 23 November 2022 Yusuf died at Sheffield Children's Hospital. He had been transferred there from home by Yorkshire Ambulance Service on 18 November.
- 1.2 On Saturday 12 November 2022 Yusuf developed a temperature during the night and by the morning of Sunday 13 November he was feeling generally unwell. On the evening of Monday 14 November Yusuf began to complain of a sore throat. He was unable to swallow solids and was only drinking sips of water. On Wednesday 23 November 2022 Yusuf died at Sheffield Children's Hospital. He had been transferred there from home by Yorkshire Ambulance Service on 18 November. His mother had taken him to his GP practice on Tuesday 15 November, he was complaining of a sore throat and was prescribed antibiotics by an advanced nurse practitioner. His parents took him to Rotherham Hospital Urgent & Emergency Care Centre (UECC) later that evening. Yusuf was there for six hours and was seen in the early hours of the morning when he was discharged with a diagnosis of severe tonsillitis and an extended prescription of antibiotics. He remained unwell at home over the next two days, developing further breathing and swallowing difficulties and was seen by his GP on the morning of Friday 18 November. Additional antibiotics were prescribed to cover a possible chest infection. Shortly after this his family became so concerned they called an ambulance. Yusuf was taken directly to Sheffield Children's Hospital at the request of his family where he was triaged immediately. After eight hours he was admitted to Ward 4. On Monday 21 November Yusuf's clinical indicators deteriorated markedly and he was admitted to and subsequently intubated on the paediatric intensive care unit (PICU). Despite a wide range of treatments, Yusuf developed multi-organ failure and suffered several cardiac arrests which he did not survive.
- 1.3 On 21 November Yusuf's uncle made a complaint to The Rotherham NHS Foundation Trust stating that the family believed Yusuf should have been admitted to the hospital earlier in the week and that his deterioration could have been prevented had he been admitted into the children's ward and given intravenous (IV) antibiotics.
- 1.4 Following a meeting with the family, on 2 December the Trust converted the complaint into a serious incident requiring investigation and South Yorkshire Integrated Care Board commissioned an external independent investigation into the care and treatment that had been given.

Approach to investigation

- 1.4 The terms of reference for this investigation are set out in Appendix 1. The investigation was led by a partner and director from Niche Consulting and the panel included clinical expertise from a consultant paediatrician with experience in emergency paediatric care, a GP who is a senior partner and primary care board member on an integrated care board, and a consultant paramedic in emergency care. None of the team members had conflicts in this case and all are independent of the services under review.
- 1.5 The parties involved in the investigation are:
 - York Road Surgery (Yusuf's primary care provider)
 - Yorkshire Ambulance Service NHS Trust
 - The Rotherham NHS Foundation Trust
 - Sheffield Children's NHS Foundation Trust
- 1.6 We requested full and unredacted clinical records, including all blood test results, for Yusuf from his medical history in primary care, prior relevant medical interventions at Rotherham and all records

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from 15 to 23 November 2022. We requested incident reports, investigation reports, relevant policies and procedures from all parties.

- 1.7 We interviewed two primary care staff, six staff from Rotherham Hospital (paediatric UECC and the children's ward) and four PICU consultants from Sheffield Children's Hospital.
- 1.8 We conducted a site visit on 10 March 2023 at Rotherham Hospital where we saw the UECC and its layout and visited the children's assessment unit and the children's ward. During this site visit we spoke with the security manager who showed us the CCTV footage of the UECC for the night of 15 November. We also met with the deputy divisional lead, staff on the children's ward and staff in the UECC. This gave us the opportunity to view facilities and talk with a wider range of staff about how services are expected to work. The full CCTV footage was provided to us on 17 April 2023. We would like to thank all staff who met with us and provided information.
- 1.9 We met with Yusuf's family on 13 January 2023 and again on 10 March. They were accompanied by a representative partner from Bindmans legal services. The family provided a chronology of events on 7 March 2023 with photographs and videos of Yusuf's presentation from 15 to 21 November 2022.
- 1.10 We offer our sincere condolences to his family and thank them for their time and insights.
- 1.11 A key theme of this case is the experience of Yusuf's family as they sought help from four different NHS services for Yusuf. They have been diligent in describing to us how this felt at each interaction and have provided their perspective on events. We recognise their distress and we do not wish to diminish how this must have felt for them at the time and since in our findings. How his family felt they were treated and spoken with is very real and is an important reflection for everyone involved in this very sad situation. We hope our recommendations in relation to listening to and engaging with worried parents will be addressed by all organisations involved.

Summary findings

- 1.12 Yusuf was a five-year-old boy who died of respiratory failure. The medical cause of death certificate states: 1a) type 1 respiratory failure; 1b) pneumonia; 2) tonsillitis.
- 1.13 This was secondary to an unusually severe inflammatory response which occurred at the end of a 10-day long illness. The illness initially had the features of a fairly benign childhood infection, but it did not respond to the usual treatments of upper and lower respiratory tract conditions. Primary and secondary care reviews were appropriate, with a timely admission to Sheffield Children's Hospital and subsequent extensive investigations and therapeutic attempts. However, these did not stop the progress of his illness. The initial observations and blood test results did not suggest serious disease. Yusuf was appropriately treated for possible sepsis, multiple causes of potential pneumonia,¹ asthma and tonsillitis, but the response to all therapies tried was minimal and short-lived. No causative organism has been found on any microbiology, virology or fungal tests. A diagnosis of Lemierre's syndrome² would have linked the initial tonsillitis with a later pneumonia, but

¹ Pneumonia is generally defined as an infection that affects one or both lungs. It is a severe inflammation of the lungs in which the alveoli (tiny air sacs) are filled with fluid. This may decrease the amount of oxygen that the blood can absorb from the air breathed into the lung.

² Lemierre's syndrome is a severe condition characterised by thrombophlebitis of the internal jugular vein and bacteraemia caused by primarily anaerobic organisms, following a recent oropharyngeal infection. It is a rare and potentially severe complication of bacterial infections that usually affects previously healthy adolescents. It most commonly develops in association with a bacterial throat infection (sometimes in association with the Epstein-Barr virus). The bacteria responsible is usually *Fusobacterium necrophorum* but other bacteria can be responsible. The initial infection spreads into tissues and deep spaces within the neck, leading to the formation of an infected blood clot (septic thrombophlebitis) in the internal jugular vein. This then circulates into the blood resulting in an infection spreading most commonly to the lungs and other parts of the body e.g. heart and kidneys. This can lead to severe complications such as respiratory distress syndrome due to pulmonary emboli, damage to other organs and/or septic shock (about seven per cent of cases). It can be diagnosed on the basis of signs and symptoms, various blood tests and imaging studies. The mainstay of treatment is antibiotic therapy. A beta-lactamase resistant beta-lactam antibiotic is recommended as an empiric therapy because there have been case reports of treatment failures with penicillin secondary to beta-lactamase producing *Fusobacterium necrophorum*. Metronidazole, clindamycin and a carbapenem antibiotic (meropenem) were all prescribed

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investigations for this did not confirm the diagnosis. A post-mortem may have helped refine an understanding of Yusuf's underlying pathology, but no post-mortem was carried out.

- 1.14 With hindsight, Yusuf's presentation was not typical of tonsillitis, streptococcal sepsis, asthma or simple community acquired pneumonia. Children do sometimes present atypically and so we have looked critically at his clinical pathway and at whether there were any missed opportunities to stop the course of his disease.
- 1.15 Yusuf's family is also concerned that a lack of beds at Rotherham Hospital was the reason he was not admitted for IV antibiotics when he visited the UECC on 15 November. They have asked whether he might have survived if he had received IV antibiotics at that time and they are interested in the link between tonsillitis and pneumonia, both of which appear on his death certificate.
- 1.16 Our investigation shows that if it been considered necessary to admit Yusuf on 15 November, based on his presentation and the clinical observations made, a bed would have been found. We visited the children's ward and interviewed staff and it is clear there are both physical space and procedures in place to admit a child when needed. The commissioned bed numbers are 22 (10 on the assessment unit and 12 on the children's ward). Appendix 2 shows the bed capacity figures for the children's assessment unit (CAU) and the children's ward for 15-18 November. There is an expectation that bed capacity will be flexed³ beyond this if there is a clinical need because the physical space is available. Should there be capacity problems the escalation flow chart in "*the timely transfer for acute medical patients under the age of 16*" references diverting patients in consultation with the executive team. On the night of 15 November admissions were being made into the unit despite the UECC, children's assessment unit and ward being very busy. Between the hours of 1am and 5am on 16 November, between 17 and 19 bed spaces were occupied on the CAU and the children's ward.
- 1.17 We explore the link between Yusuf's tonsillitis and his subsequent respiratory failure in detail in this report. Without a post-mortem it is not possible to be conclusive; however, it is evident that Yusuf experienced a highly unusual inflammatory response and the antibiotics and other treatments⁴ had no impact. The trajectory of his presentation could not have been predicted and the sudden deterioration in his clinical indicators on 21 November was unexpected. He did not respond to oral antibiotics from 15 to 18 November or IV antibiotics from 18 to 21 November or in the days that

to Yusuf – metronidazole was the most effective. It is usually required for one to two weeks parenterally (IV) then a further 10 days orally.

Arane, K and Goldman, R (2016) [Fusobacterium Infections in Children](#)

³ The timely transfer for acute medical patients under the age of 16 from UECC Standard Operating Procedure states: *Once the decision to admit has been made and contact is made with the Children's Ward staff by the Paediatric Nurse in Charge in UECC, then the patient should be admitted within 30 minutes of this referral. If due to capacity, there will be challenges in relation to accepting or transferring this admission within 30 minutes of the referral, then this needs to be raised with a planned time frame by which the child can be moved to the ward, including exploring what additional support can be sourced (e.g. Children's ward supporting by collecting the patient if acuity allows). It is essential that both areas take into consideration the acuity and activity in each area ensuring that the safety of the patients for transfer and the safety of patients in other paediatric areas within the Trust are taken into consideration.*

If the ward and CAU are full but there are planned discharges, then the patient must be transferred and the Children's Ward and CAU will need to flex over the defined bed capacity for a short period of time to allow the transfer to take place. This may need some additional nursing resource to support this which can be sought through the Nurse in Charge (NIC), Ward Manager or Matron. If there are no planned discharges and the children's ward or CAU is full then the paediatric registrar needs to be informed and the on-call Consultant will need to be contacted.

If there is high activity or acuity in the Paediatric UECC department or there is a child or young person in the resuscitation area, then support may be required to transfer these patients to the Children's Ward or CAU. This will need to be managed alongside the activity on CAU, the Children's Ward, SCBU, and maternity services. Should there be any delay in this support this needs to be raised as soon as the challenges are identified.

Should there be any challenges following this procedure then the escalation flow chart must be followed ensuring that clear communication is maintained at all-time[s] along with professional courtesy and respectful behaviour. Any delay must be clearly communicated between both areas and the child, young person and family updated on any delay in transfer. Update the site management team so they are aware of any delays from a decision to admit perspective.

⁴ Oxygen, anti-viral, anti-inflammatory and anti-fungal medications alongside drugs and nebulisers for asthma and to ease work of breathing e.g. dexamethasone, aminophylline, salbutamol.

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followed. After Yusuf's death, the PICU team considered a range of possible causes, but they have all been inconclusive because of conflicting clinical indicators. Whilst on intensive care there were investigations that could not be conducted because of the urgency of the situation, for example, a computerised tomography (CT) scan, a bronchoscopy and biopsy of the lungs, pernasal swab for pertussis (whooping cough), more specific tests for rarer infections and a bone marrow biopsy. These are investigations the PICU team would have wished to conduct had it been possible.

- 1.18 To consider whether Yusuf had a chest infection that had spread from his tonsillitis a definition of the term 'pneumonia' as used in this case is important. In lay terms it can be seen as a chest infection. However, in this case while the term was appropriately used in discussions with his family, and early indications were that he might have had a chest infection, it was likely that this was not the only factor in this case.
- 1.19 Pneumonia is generally defined as an infection that affects one or both lungs. It is a severe inflammation of the lungs in which the alveoli (tiny air sacs) are filled with fluid. This may decrease the amount of oxygen that blood can absorb from the air breathed into the lung. In the absence of bacteria having been collected from the lung either by bronchoscopy or in sputum, it is a clinical diagnosis based on the chest X-ray appearances, blood test results and – with hindsight – the response to antibiotics. Yusuf's chest X-ray was consistent with him having pneumonia but the blood tests and lack of response to antibiotics call the diagnosis into question (in terms of an infective cause). Inflammation within the lungs can look like pneumonia on a chest X-ray. Persistent pulmonary infiltrate results when a substance denser than air (e.g. pus, oedema, blood, surfactant, protein or cells) lingers in the lung parenchyma.⁵ The leukemoid reaction⁶ on 22 November was probably responsible for the chest X-ray findings; his lungs were probably full of white blood cells. The intensivists⁷ at Sheffield mentioned "*hepatisation*" of the lung where the organ begins to stiffen. This is seen in a severe inflammatory response, usually secondary to an infection. There is no good evidence that he had a primarily infective type of pneumonia, and he was on treatment for a range of possible bacterial, viral and fungal causes. A post-mortem may have helped refine an understanding further.
- 1.20 The term sepsis was frequently referred to in the clinical assessments and investigations completed throughout Yusuf's care. Sepsis is an important consideration to keep under constant clinical review. However, there was no evidence of sepsis. Clinical signs that were consistent with sepsis were present when the ambulance crew took him to Sheffield Children's Hospital, but they were not specific and further assessment at Sheffield Children's Hospital and his fairly unremarkable, initial blood tests do not support a diagnosis of sepsis. He was shocked⁸ (had an inability to carry sufficient oxygen to the tissues and remove waste from them) towards the end of his life and this was secondary to the severe inflammatory reaction, but it was not necessarily infective.
- 1.21 We had the benefit of hindsight when reviewing Yusuf's blood results and his presentation in detail. While providing a posthumous diagnosis is not part of the scope or purpose of this investigation, we have considered a range of possible clinical presentations including underlying malignancy (e.g. early leukaemia) and early onset Type 1 diabetes. The available blood results were also shared with an independent haematologist, which meant a wide range of early presenting underlying malignant conditions could be discounted.
- 1.22 A wide range of non-malignant related conditions involving throat infections were also considered by the investigation and the PICU team and were either discounted as explanations for his presentation or could not be confirmed. These included glandular fever (from the Epstein-Barr (EBV) virus or the cytomegalovirus (CMV)), pertussis (whooping cough), epiglottitis (brought on by

⁵ The functional tissues of an organ as distinguished from the connective and supporting tissue.

⁶ An increase in the white blood cell count, which can mimic leukaemia.

⁷ Intensivists are also known as critical care doctors.

⁸ National Center for Biotechnology Information (updated July 25, 2022) [National Library of Medicine. StatPearls – Shock](#)

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haemophilus influenzae type B or group A streptococcus), an invasive fungal infection, diphtheria and Lemierre's syndrome.

- 1.23 It is important to note that Yusuf's mother was experienced in the management of his asthma and his repeated respiratory infections, and she said on multiple occasions in UECC and subsequently that she was very concerned about him (and she was supported by her brother in this). An admission to the children's ward at Rotherham Hospital, which, while not clinically indicated, could have been given more consideration and could have been discussed with his family given their concerns. We are of the view that when a parent or relative of a child expresses such concern and distress in the presentation of their sick child, the parental experience should be considered formally. This is a key point of learning for the future assessment of sick children and is included in our national recommendations.
- 1.24 We have been asked to comment on the actions taken immediately after the incident. We have defined the incident as meaning the complaint made by the family (on 21 November) to Rotherham Hospital sharing their concerns about the failure to admit Yusuf. The Trust responded promptly to this complaint. Details of the complaint procedures were sent to Yusuf's uncle after his initial approach, all interactions were appropriately recorded, as was the wish for the chief executive officer to be made aware of the complaint. The complaint was reviewed by the Incident Review Panel on Friday 25 November. By Monday 28 November the chief executive officer had determined that this case would be declared a serious incident requiring investigation. A 72-hour report was completed, and a serious incident form was logged on 29 November. The chief executive officer met with Yusuf's family on 30 November to apologise. Appropriate duty of candour processes were followed, and his family were informed on 2 December that an independent investigation would be commissioned. The Trust's response was prompt and its processes were well managed.
- 1.25 The Trust completed the initial 72-hour review and, on the basis of this case, they have begun the recruitment of additional medical staffing for the UECC.
- 1.26 We have made additional recommendations which, while they would not have changed the course of events for Yusuf, should be implemented to ensure there is learning from this case.

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Recommendations

National recommendation:

Recommendation 1: At times there was conflict between relatives, paramedic teams and hospital staff while Yusuf's family attempted to access urgent care.

National research should be commissioned to look into why and when parents raise concerns about their children's acute presentation to health services. There is a need for the development of a mechanism which will objectively measure this, enable empowerment for parents without conflict and be embedded into a system of escalation which enables the safest response. This could build upon the parental concerns work being undertaken by the Great North Children's Hospital (Newcastle Upon Tyne NHS Foundation Trust) and other national and international initiatives. An approach by the SPOT programme to the National Institute for Health and Care Research (NIHR) might help facilitate research funding.

Recommendation 2: Different paediatric observation tools (for example, the Paediatric Observation Priority Score (POPS) and Paediatric Early Warning System (PEWS)) were used by different providers across the care pathway.

We are aware of the efforts of NHS England, the Royal College of Nursing and the Royal College of Paediatrics and Child Health (RCPCH)⁹ to agree a national PEWS system¹⁰ through the System-wide Paediatric Observations Tracking (SPOT) programme. We understand there are plans to launch this for paediatric inpatients this year. We would recommend that all Trusts are encouraged to use the national version¹¹ on its launch and that work continues to align POPS (in use in emergency departments) with the new PEWS tool¹².

Recommendation 3: Parents and relatives raised repeated concerns over time and across providers that his presentation was not his usual self. They took videos and pictures to document his presentation in an attempt to demonstrate their concerns. The history of concerns over the preceding week prior to admission was not clearly apparent in shared records across the system and relied on parents to repeatedly raise them.

- On assessment of the sick child the collation of observations across different providers and locations needs to recognise the history of parental concerns/multiple presentations to different services and inform decision making when determining the need for escalation.
- The SPOT programme should look at ways of embedding patterns of consistent or repeated concerns from parents (and clinicians) into future strategies for assessing the escalation requirements of a sick child.

⁹ [Paediatric Early Warning System \(PEWS\) - developing a standardised system for England | RCPCH](#)

¹⁰ <https://www.rcpch.ac.uk/resources/paediatric-early-warning-system-pewssystem-developing-standardised-tool-england>

¹¹ There is a paper based version intended for launch in September 2023 (delayed from 23 May 2023) with the digital specification currently being consulted on later in 2023.

¹² We are also aware that work is being conducted at pace to extend the PEWS tool into the emergency department setting. This will be extended into primary care thereafter. This is managed under the SPOT programme.

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Primary care recommendations

Recommendation 1: Primary care communication

Yusuf's mother was expecting to see a GP and not a primary care nurse practitioner when she made an appointment for Yusuf.

Patients who make appointments with their GP surgery should be told which healthcare professional they (or their family member) will be seeing, including their name and position.

Recommendation 2: Primary care assessment

The assessments in primary care could have been more comprehensive (although there was no evidence this impacted the outcome).

- a. All primary care clinicians who are assessing sick children should have training specific to that assessment, for example, [Spotting the Sick Child](#)
- b. When assessing sick children, clinicians should be aware of available local and national guidelines, for example:

[NICE Guidance: Feverish Children – Risk Assessment](#)

[NICE Risk Stratification Tool for Children Under 5 years](#) or [UK Sepsis Trust GP Paediatric Sepsis Decision Support Tool for Children Under 5 years](#)

[NICE Risk Stratification Tool for Children Aged 5–11 Years](#) or [UK Sepsis Trust GP Paediatric Sepsis Decision Support Tool for Children Aged 5–11 Years](#)

Recommendation 3: Primary care equipment

A functional paediatric pulse oximeter¹³ was not used when Yusuf attended the GP surgery for his appointment.

All practices should have access to age-appropriate equipment, including pulse oximeters, so clinicians can accurately assess sick children when they present.

Recommendation 4: Onward referral from primary care

There was a lack of clarity in primary care about accessing the opinion of paediatric services at Rotherham Hospital.

To avoid future ambiguity, a written protocol should be produced for the agreed pathway and criteria for referring on for further paediatric assessment from primary care. This should include: the role of the children's assessment unit and the role of the paediatric urgent care centre, how to access an urgent paediatric opinion and clarity on direct access to the children's ward.

Recommendation 5: Patient information

Staff were unaware of the website resource Healthier Together which contains information leaflets and advice (for safety netting).

- Parents should be directed to the Healthier Together website for written patient information.
- Nursing and medical staff working in primary care should be aware of this resource. Leaflets should be printed if parents do not have internet access.

¹³ A pulse oximeter is a small device placed on the finger to measure heart rate and oxygen saturations. Paediatric pulse oximeters are smaller than those used for adults.

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Yorkshire Ambulance Service NHS Trust recommendations

Recommendation 1: Conflict resolution and listening to family members

Protocols were appropriately considered in transporting Yusuf to Rotherham Hospital, but there were difficult conversations between Yorkshire Ambulance Service staff and the distressed parents as they sought help from the paramedics for their son who was unwell. This added a slight delay to the transfer.

- All clinical teams are to be required to attend the regular conflict resolution training sessions provided by the Trust to support the management of conflict in patient care.
- The training should be extended to include having difficult conversations, working with worried parents and cultural differences in conflict.
- This case should be included as a case study as part of the face-to-face training provided.

Recommendation 2: Clinical assessment

While they did not affect the prompt access to care, the clinical examinations and physiological observations carried out by the paramedics did not fully comply with local or national guidelines.

Essential examinations and physiological observations must be completed and documented in the clinical records in line with Joint Royal Colleges Ambulance Liaison Committee (JRCALC) guidelines. These must include heart rate, capillary refill time, respiratory examination (including the work of breathing (WOB)¹⁴ and auscultation¹⁵) and the hydration status for children who present as unwell.

Recommendation 3: Administration of oxygen guidelines

The administration of oxygen was not in line with national guidance although there was evidence that the amount given did have a positive effect on the patient's condition.

For children who have been assessed as hypoxic, oxygen must be administered in line with JRCALC guidelines.

Recommendation 4: Transport protocols

Given the clinical findings, a pre-alert should have been sent to the receiving hospital, but this did not take place.

Pre-alert protocols must be adhered to so that receiving hospitals can prepare for and respond appropriately to the arrival of very sick patients.

¹⁴ The energy expended to inhale and exhale.

¹⁵ Listening to sounds from the heart, lungs or other organs.

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The Rotherham NHS Foundation Trust recommendations

Recommendation 1: Conflict resolution and listening to family members

Difficult conversations took place between relatives and hospital staff as Yusuf's family attempted to access urgent care.

- All clinical teams are to be encouraged to attend simulation communication training on conflict in patient care.
- It is advised that a reminder be given to staff about responding to parent concerns (as per the amber flag in sepsis guidance). History taking and listening carefully to a concerned parent or relative should be uppermost in the minds of staff presented with a very sick child.

Recommendation 2: Recording systems and paediatric information fields

There were minor recording errors that IT solutions could solve. Namely that the ST6 doctor was still being recorded as a foundation doctor, the child's height was pulled through from SystmOne¹⁶ and the BMI calculations used height/weight (kg), which is more appropriate for adults, when BMI centiles are more appropriate in paediatric care. Accurate weight/height and BMI centiles are essential in paediatric decision-making. The discharge letter appears to use the Early Warning Score (EWS) as the field in the EPR (when POPS is used for children).

- The Trust should examine why there remain problems with changing the grades of staff in the electronic patient record and resolve this for the ST6. They must also establish if it is a wider issue.
- SystmOne should be reviewed with paediatrics in mind. Height and weight recordings should be pulled into records accurately and BMI centiles should be used instead of the adult oriented calculations for BMI. It should also be clear whether POPS or EWS scores have been assessed.

Recommendation 3: Staffing levels in the UECC

Medical staffing levels were below expected levels on the night of 15 November.

- The Trust should assess medical and nursing staffing levels in the paediatric UECC overnight to ensure capacity meets demand. This should include the number of clinicians, their seniority and their level of paediatric experience.
- The Trust should review whether to have paediatricians in the paediatric UECC at all times who can oversee the care of children presenting with medical complaints.
- The Trust should review the feasibility of having a children's assessment unit, ideally co-located with the UECC, open 24 hours a day with medical and nursing staff trained in the care of acutely unwell children.

We understand that these recommendations have already been acted on at Rotherham; a progress report on the changes would be helpful.

Recommendation 4: Patient information

Staff were unaware of the website resource Healthier Together which contains information leaflets and advice (for safety netting).

- Parents should be directed to the Healthier Together website for written patient information.
- Nursing and medical staff working in the paediatric UECC should be aware of this resource. Leaflets should be printed if parents do not have internet access.

¹⁶ The electronic patient record system used at The Rotherham NHS Foundation Trust

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Sheffield Children's NHS Foundation Trust recommendations

Recommendation 1: Clinical care

We did not see evidence of cannula patency¹⁷ having been documented and cannot be assured of the quality of cannulation management.

The Trust must ensure that all staff giving antibiotics intravenously check the line is unobstructed before each dose and document regular checks on peripheral IV lines when in situ (visual infusion phlebitis (VIP) score).

We noted time delays between the prescribing of drugs and their administration.

The Trust must ensure that prescribed drugs (in particular antibiotics) are given as soon as possible after prescribing decisions are made. This should be audited in the emergency department (ED), the wards and the PICU.

Recommendation 2: Post-mortems in children who die unexpectedly

Yusuf did not have a post-mortem, which has meant there was a missed opportunity to understand his underlying pathology more definitively.

- The Trust should review its criteria and decision-making in relation to undertaking hospital post-mortems for children who die unexpectedly. This should result in readily available Trust guidelines, considering the values of a multicultural population.
- Support given to clinicians facing conversations with families in difficult situations should be reviewed to ensure it is adequate, in particular the view of PICU staff should be considered.

Recommendation 3: Nutritional assessments

A nutritional risk assessment (STAMP) was not completed. The impact of pre-admission reduced nutritional intake was not assessed.

- The Trust should ensure the STAMP screening is completed accurately on admission as per Trust policy.
 - The Trust should review its STAMP guidance to ensure that pre-admission nutritional status is adequately considered in scoring and care planning.
- The Trust should make clear what action is expected when a high risk malnutrition score results from STAMP screening with contingencies agreed for out of hours and weekend assessments.

¹⁷ That the line is open and not blocked. A patent IV line is one that is correctly placed, allowing the treatment to flow directly into the patient's vein. A poorly placed IV is not patent and can cause negative side effects.

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Part 2 – Chronology of events

This chronology is a high level summary of Yusuf's movements and key contacts with services. Detailed information has been removed to protect confidential information. Our summary, recommendations and analysis in relation to the case can be found in full in the remainder of this report.

Early childhood

- 2.1 Yusuf was born in August 2017. In the first year of life Yusuf presented with several upper respiratory tract infections. By the age of 15 months Yusuf had a diagnosis of possible asthma with coughing at night. At two years and six months (February 2020) a further admission to hospital required another overnight stay in the children's ward at Rotherham Hospital. The assumption of an asthma diagnosis continued. By September 2020, when Yusuf was three years old, his asthma appeared to be getting worse and a referral was made to the paediatric asthma clinic. As of September 2022 Yusuf continued to present with wheezing symptoms to his GP practice. On 3 October 2022 Yusuf attended the asthma clinic again.

12 to 15 November 2022

Primary care at York Road Surgery

- 2.2 On Saturday 12 November 2022 Yusuf developed a temperature during the night and by the morning of Sunday 13 November he was feeling generally unwell. On the evening of Monday 14 November Yusuf began to complain of a sore throat.
- 2.3 On Tuesday 15 November his mother requested an appointment at York Road Surgery. Yusuf was assessed by an advanced nurse practitioner (at 12:36).

Rotherham General Hospital

- 2.4 Yusuf's mother was concerned about her son's condition. She decided to call NHS 111 for advice.¹⁸ The call was made at 22:46:38. She was advised by NHS 111 at 23:01:42 to take him to the UECC.
- 2.5 Yusuf arrived at the UECC at approximately 23:15 on 15 November 2022 and he was admitted into the paediatric part of the UECC at 23:21. He was triaged (seen by a nurse for assessment) at 23:28:15. The UECC was busy that night. Yusuf was triaged within seven minutes of arriving in the paediatric UECC. However, it was just over six hours (362 minutes) before he saw a doctor.
- 2.6 At 01:23:16 Yusuf was transferred to a cubicle. At 01:49 Yusuf was recorded as being comfortable in the side room. Clinical professionals attended the cubicle again at 03:29.
- 2.7 At 05:17 Yusuf was seen by a doctor. Yusuf left the UECC at 05:35.

16 to 18 November 2022

- 2.8 By 18 November there had been no improvement in his condition. At 08:37 a face-to-face appointment at 11:30 was arranged by telephone call. Yusuf was seen at 11:22 by a regular locum GP. The GP determined Yusuf still had severe tonsillitis and broadened the spectrum of antibiotics by adding erythromycin 250mg/QDS.
- 2.9 At 12:35 his uncle made a call to the children's ward at Rotherham General Hospital. At 12:50, having been unable to secure an admission to the ward, Yusuf's family decided that he needed to go to Sheffield Children's Hospital. At 12:53 a friend advised them *"to call 999 and get [him taken] to the children's hospital"*.

¹⁸ NHS 111 is run locally by Yorkshire Ambulance Service.

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Yorkshire Ambulance Service

- 2.10 A 999 call to Yorkshire Ambulance Service at 12:59 was made by Yusuf's mother. The call was coded as a category 1,¹⁹ the most life-threatening category, and the call taker stayed on the line and arranged for an ambulance to attend. Six minutes and 16 seconds into the call an ambulance and paramedic crew arrived and by 13:08:48 paramedics were with Yusuf. This was within the national time target of eight minutes.
- 2.11 At 13:20 the administration of 2 litres (L) of oxygen was started. At 13:30 his uncle rang 999 to ask for Yusuf to be taken to Sheffield Children's Hospital rather than Rotherham Hospital. By 13:48 Yusuf was being taken into the ambulance to go to Sheffield Children's Hospital ED. The ambulance left for the hospital at 14:00.

Sheffield Children's Hospital – ED

18 November 2022

- 2.12 At 14:34 the ambulance arrived at Sheffield Children's Hospital ED. Yusuf was handed over immediately and triaged by the ED team. At 14:47:01 his observations were recorded. At 15:13 he was seen by a doctor in the Sheffield Children's Hospital ED.
- 2.13 At 16:40 Yusuf was clerked²⁰ by the senior house officer. He was reviewed by the ED consultant at 17:10. A chest X-ray was taken at 17:56. At 18:00 he was examined by the paediatric registrar. The chest X-ray was recorded as nothing abnormal detected (NAD) at 18:00. The formal report was provided at 12:57 on 19 November which indicated some lower airways inflammatory/infective change. At 18:30 he was cannulated, and bloods were taken.
- 2.14 At 19:15 IV benzylpenicillin²¹ (790mg QDS²²) was started and this was given regularly until the early hours of 21 November. At 20:25 the ENT registrar on call recommended a bacterial throat swab, increasing the dexamethasone and IV metronidazole antibiotics²³ (120mg TDS²⁴) were to be added to IV benzylpenicillin. The first dose of IV metronidazole was given at 01:00 on 19 November with the IV benzylpenicillin as instructed.
- 2.15 At 22:27 Yusuf was admitted to Ward 4. He had spent eight hours in the ED. Appendix 4 shows staffing levels across the ED, Ward 4 and PICU from 18 to 23 November.

Sheffield Children's Hospital – Ward 4

- 2.16 At 23:30 Yusuf was seen by a registrar (ST8) because of stridor²⁵ and increased WOB. Salbutamol was not having the required effect. Stridor was not observed but he was snoring. He had good bilateral air entry to his lungs, was well perfused and did not have a wheeze. The plan was to continue treatment (IV fluids, IV antibiotics and steroids, repeat bloods/blood gases and blood glucose levels).

19 November

- 2.17 On the morning of 19 November he was seen at 09:00 by a junior doctor (ST3) from ENT.

¹⁹ A time critical life-threatening event needing immediate intervention and/or resuscitation.

²⁰ Clerking is the first and most important contact a medical team has with a patient and involves documentation of a clinical examination.

²¹ The IV version of oral Penicillin V.

²² 50mg/kg based on a body weight of 15.8kg.

²³ Metronidazole works on anaerobic bacteria, benzylpenicillin on aerobic bacteria. Metronidazole was added as the antibiotics for aerobic had not been effective.

²⁴ 7.5mg/kg body weight.

²⁵ Stridor breathing is noisy breathing that occurs due to obstructed airflow through a narrowed airway. Stridor breathing is not a diagnosis, but a symptom or a sign that points to a specific airway disorder. It can present as a high-pitched sound made on breathing in.

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- 2.18 Yusuf was seen on the post-take ward round²⁶ at 12:15 by the on-call consultant paediatrician (diabetes team), and at that time was being given IV metronidazole, IV benzylpenicillin, dexamethasone and had been prescribed Oramorph. He had good bilateral air entry with no added sounds and did have conducted sounds.²⁷ His urea and electrolyte results were normal (his potassium had normalised again). His CRP, an indicator of inflammation, was noted as 40. The impression was that he was stable. The antibiotics would continue, and he was to be encouraged to drink.

20 November

- 2.19 On 20 November Yusuf was seen at 10:00 by an ENT registrar. He was maintaining his oxygen saturations on 4L oxygen and did not have a temperature. He had slough on both tonsils and no stridor. The antibiotics were to continue, and he was still to be given dexamethasone TDS. It was hoped his oxygen could be gradually decreased (to levels of 94-98% on air), although his saturations kept dropping on air. A glandular fever screen (for EBV and CMV) was requested as this can present with large, sloughy tonsils and would not be responsive to antibiotics.
- 2.20 At 12:10 a junior doctor (ST6)²⁸ saw Yusuf. His bacterial throat swab had come back negative. He had begun to show some mild subcostal recession.²⁹ The plan for his treatment was to continue his IV antibiotics and wean him off oxygen if possible. His family recall being informed that he had *“a bit of a chest infection now”*.

21 November

- 2.21 Overnight Yusuf had continued breathing difficulties and he began to complain of pain in his abdominal area. According to his family's recollection, he was seen in the early hours of the morning of 21 November 2022 (approx. 02-03.00) by a doctor who listened to his chest.
- 2.22 Video from his parents shows Yusuf with breathing difficulties at 07:40 and was coughing. At 08:15 he was seen by the night doctor (ST2). A salbutamol/ipratropium nebuliser was given at 08:30.
- 2.23 At the ENT ward round at 09:00 Yusuf's PEWS was 4+. On examination he had grade 4³⁰ tonsils still with exudate, multiple raised neck lymph nodes on both sides. The ENT impression was tonsillitis, a lower respiratory tract infection and asthma. By 09:18 his PEWS score had begun to increase in a more sustained manner and was 6+ because of his increased respiratory rate and heart rate. This PEWS score increased to 7+/8+ within the hour.

Sheffield Children's Hospital – PICU

- 2.24 By 10.00 on 21 November Yusuf had deteriorated significantly. The impression was now of a severe acute asthma exacerbation which was life-threatening and there were concerns about partial airway obstruction, tonsillitis and a lower respiratory tract infection.
- 2.25 At 10:40 there was no significant improvement and the consultant on call was asked to see him. High dependency unit and consultant ENT reviews were requested.
- 2.26 At 11:05 a referral to the ICU was made and discussed with the PICU consultant. It was agreed that Yusuf needed ventilation. At 11:45 he was seen by the ENT consultant, the anaesthetic registrar, the PICU team and the consultant paediatrician.
- 2.27 At 12:00 the medical team wanted to retrieve Yusuf's Covid-19 swab for referral to virology. His throat swab was negative for bacterial infections, so this was to look for any possible viral cause of

²⁶ Ward round carried out by an on-call consultant to review the previous days admissions.

²⁷ Noises from the upper airway.

²⁸ Registrar in their sixth year of training.

²⁹ The sucking in of the abdomen below the ribs. This is another sign of WOB and it can be a result of a blocked upper airway.

³⁰ Tonsils are graded on a scale from 0 to 4. Zero means they have been removed up to 4 which means that they are very swollen and lead to a blockage in the airway.

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his condition. ENT were also considering a 'hot'³¹ tonsillectomy and a nasoendoscopy³² or microlaryngobronchoscopy³³ to look at the upper airway. His PEWS score was 12/13.

2.28 At 13:30 Yusuf was in PICU. His chest X-ray showed a right lung consolidation.

2.29 At 17:00 his chest X-ray was reported as showing possible Lemierre's syndrome. Ceftriaxone was prescribed and a 24-hourly infusion was begun at 18:00. However, by 19:30 Yusuf had deteriorated again with resistant WOB. He was intubated at 20:00.

22 November

2.30 An ultrasound scan was taken at 11:44 on 22 November to look for cervical lymph nodes to investigate a possible diagnosis of Lemierre's syndrome. This showed results that were not consistent with thrombophlebitis³⁴ Lemierre's syndrome. A further chest X-ray taken at 13:10 was discussed with Yusuf's parents.

2.31 By 16:30 the PICU team were looking to further interventions including noradrenaline infusions and nitric oxide. Yusuf was in Type 1 (hypoxic) respiratory failure. A further chest X-ray was taken at 16:42 showing ongoing white out/lung collapse.

2.32 Physiotherapy notes suggest he was bleeding when being suctioned – this suggested pulmonary haemorrhage secondary to multi-organ failure and disseminated intravascular coagulation (DIC).³⁵ This type of bleeding can also be seen in hepatisation syndrome³⁶ secondary to severe pneumonia.

2.33 At 19:00 on 22 November the PICU team decided to put Yusuf in a prone position.³⁷ They also tried high-frequency oscillatory ventilation (HFOV).³⁸ He was being considered for extracorporeal membrane oxygenation (ECMO)³⁹ if he did not improve with HFOV. The antibiotic clindamycin⁴⁰ was added to the spectrum of existing medication. The PICU team also started treatment for potential fungal infections.

2.34 A leukemoid reaction⁴¹ was noted at the same time. This means there was a very high WCC and it may have been an underlying malignancy that was causing this condition. A blood film was appropriately requested to rule out an underlying malignancy (diagnoses like leukaemia). However, Yusuf was recorded as being hypotensive⁴² and in stage 3 of acute kidney injury (AKI).⁴³

2.35 At 20:40 it was recorded that the PICU team had further discussions with microbiology and chased the blood-borne virus screen, galactomannan test (for aspergillus infections⁴⁴), b-glucan (for invasive fungal infections) and immunoglobulin (Ig) levels (for an immunodeficiency). The

³¹ An emergency tonsillectomy.

³² A procedure to look at the inside and back of the throat.

³³ A procedure to look at the larynx, trachea and bronchi (upper lungs).

³⁴ An inflammatory process that causes a blood clot to form.

³⁵ DIC is a rare but serious condition that causes abnormal blood clotting throughout the body's blood vessels. DIC may develop if there is an infection or injury that affects the body's normal blood clotting process.

³⁶ Hepatisation syndrome is the alteration of lung tissue into liver-like tissue.

³⁷ Proning is a strategy of turning a patient to lie face down for a period of time in order to improve the exchange of oxygen and carbon dioxide in the lungs during mechanical ventilation.

³⁸ HFOV is a lung protective strategy. Often used as a rescue strategy when conventional mechanical ventilation has failed. It uses rapid ventilation rates with small tidal volumes and reduces ventilator-associated lung injury, especially in the context of acute respiratory distress syndrome and acute lung injury. Acute lung injury means a form of acute respiratory failure, defined by hypoxemia and the presence of bilateral infiltrates on X-ray.

³⁹ ECMO is similar to a heart-lung bypass machine. It pumps and oxygenates blood outside the body, allowing the heart and lungs to rest.

⁴⁰ A strong broad-based antibiotic prescribed to treat severe infections. It has an anaerobic as well as aerobic impact.

⁴¹ An increase in the white blood cell count, which can mimic leukaemia.

⁴² Having abnormally low blood pressure.

⁴³ AKI describes sudden damage to the kidneys that causes them not to work properly. It can range from minor loss of kidney function to complete kidney failure. AKI normally happens as a complication of another serious illness. Stage 3 is the 'middle' stage and cannot often be cured and can lead to kidney damage that is not normally reversible.

⁴⁴ Fungal infections.

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microbiologist suggested replacing the ceftriaxone with meropenem^{45 46} along with clindamycin⁴⁷ and to start immunoglobulin IV (in case of a staphylococcus infection). They would also liaise with virology to decide if Tamiflu⁴⁸ was appropriate. Caspofungin⁴⁹ was started at 22:00. Tamiflu was administered at 23:30.

- 2.36 At 21:30 microbiology also advised clarithromycin⁵⁰ as there were some features of atypical mycoplasma pneumonia showing. The first dose was administered at 23:00. A mycoplasma polymerase chain reaction (PCR)⁵¹ test was sent for testing. This test also came back negative.

23 November

- 2.37 Overnight on 22/23 November Yusuf continued to deteriorate. His right lung showed a complete white out⁵² and there was increasing consolidation of his left lung. This suggests that the antibiotic therapy was not working, and his lungs were continuing to deteriorate. He was being treated for possible sepsis with three different antibiotics, for a possible invasive fungal infection and with antivirals (Tamiflu) used to treat and prevent influenza A and influenza B. His WCC (63.55) and CRP (141) were increasing. Late that night, HFOV was being used and cautious hyperhydration to try and thin his blood was discussed with his parents. Other options were also considered including exchange transfusion.⁵³
- 2.38 Yusuf was hyperhydrated for four hours. He continued to deteriorate with a WCC of 68.6 and platelets of 57 dropping to 37. A decision was taken to refer him for ECMO if his oxygenation index worsened.⁵⁴ At 08:30 on 23 November 2022 his index was 44 and he was referred for ECMO.
- 2.39 At 09:15 Yusuf went into cardiac arrest. He passed away at 11:17 on 23 November 2022. A referral was made to the coroner at 16:30 in line with national guidance.
- 2.40 An initial complaint was raised by Yusuf's uncle with Rotherham Hospital on 21 November 2022. On 25 November the complaint was raised as an incident at the Incident Review Panel and a RED⁵⁵ internal investigation was launched. A 72-hour review was completed, and the case was designated a serious incident on 29 November. A decision to request an independent investigation was recorded on 2 December following a meeting with the CEO at The Rotherham NHS Foundation Trust on 30 November.
- 2.41 A child death review notification was completed on 23 November in line with procedures and a joint agency review (JAR) meeting was held and closed on 29 January 2023.

⁴⁵ One dose was given at 22:25. The dose was adjusted for his AKI.

⁴⁶ Meropenem is a broad spectrum carbapenem antibiotic used to treat gram-positive and gram-negative bacteria. It is used to treat severe or complicated infections when other antibiotics may not be enough.

⁴⁷ Two doses were administered: one at 22:25 on 22 November and one at 04:00 on 23 November.

⁴⁸ Tamiflu is used to treat and prevent flu.

⁴⁹ Caspofungin is an echinocandin class of medications used to manage and treat several medical conditions. These conditions include febrile neutropenia, candida infections, invasive candidiasis, oesophageal candidiasis and invasive aspergillosis.

⁵⁰ Clarithromycin is an antibiotic used to treat chest infections such as pneumonia.

⁵¹ Mycoplasma PCR test is used to test for mycoplasma bacteria which are highly resistant to antibiotics. Mycoplasma pneumonia is spread through contact with droplets from infected people and is thought to require prolonged close contact with an infected person.

⁵² Total opacification of one side of the thoracic cavity – likely due to consolidation.

⁵³ Exchange transfusion is a blood transfusion in which blood or components of blood are exchanged with other blood or blood products. It can be used to counteract the effects of changes in the blood. There is very little research evidence to back such a strategy up in this case.

⁵⁴ The oxygenation index helps predict outcomes, especially in paediatric patients and helps determine the need for ECMO. An index over 40 indicates ECMO should be considered.

⁵⁵ Grading system used by the Trust for deciding how to investigate based on seriousness of an incident.

Part 3 – Findings by care episode

Preadmission

Commentary on this care episode and points for learning

- 3.1 Yusuf had a background of what looks to be suboptimally controlled asthma. He had respiratory illnesses from a very young age which were variously diagnosed as bronchiolitis or viral induced wheeze. He was started on asthma preventative therapy (inhaled corticosteroids⁵⁶ and montelukast) at a relatively young age and these medications were started and stopped on several occasions. There was a family history of asthma.
- 3.2 Yusuf did not appear to tolerate montelukast well and struggled with the volumatic spacer for his inhalers at times. In common with many young children, he did not have many exacerbations of wheeze during the pandemic, but his asthma symptoms seemed to have been getting worse during 2022. His mother says though that by September 2022 his asthma was as good as it had ever been. There is some suggestion of faltering growth in the year before his death and his weight gain slowed over the winter period, which correlates with when he had the most episodes of respiratory symptoms.
- 3.3 Asthma can slow growth and oral steroids can affect height, although that is not usually the case with inhaled steroids. Yusuf was noted to have Harrison sulcus⁵⁷ which can be a sign of long-term respiratory issues. One of his last asthma control test (ACT)⁵⁸ scores was 16, which suggests that control was suboptimal at times. Yusuf's last recorded ACT was in December 2021. There is no strong suggestion in the way his respiratory problems or his family history are documented to suggest an alternative underlying diagnosis e.g. cystic fibrosis or an immunological problem.

York Road General Practice Surgery

Commentary on this care episode and points for learning

- 3.4 For the review of primary care we had access to the family timeline, the recordings of the telephone calls between the family of Yusuf and the York Road Surgery on 15 and 18 November 2022, the GP practice clinic records of the consultations on 15 and 18 November 2022 and the full GP clinical record – which included community notes and hospital letters. Interviews were also carried out with the primary care nurse practitioner and the attending locum GP at York Road Surgery.
- 3.5 There is a broad correlation between the family timeline and the GP records, phone calls and interviews with the clinicians. The only discrepancy was in the family recollection of the GP saying Yusuf needed IV antibiotics when he was seen on 18 November. The family recall antibiotics being recommended at that assessment. The doctor's recollection and recorded notes indicate that he advised UECC attendance if there was no improvement and said that the hospital may consider antibiotics appropriate at that time.
- 3.6 Yusuf's final illness started around the weekend of 12-13 November 2022. His mother arranged an appointment at the GP surgery on 15 November and they saw a nurse practitioner who prescribed

⁵⁶ Corticosteroids are often known as steroids and are anti-inflammatory medicines.

⁵⁷ Harrison's sulcus is an indentation on the chest roughly along the sixth rib which is usually bilateral but can also occur unilaterally. The depth of the groove varies but the deepest part always remains over the sixth costal cartilage. It is usually caused by chronic asthma or obstructive respiratory disease. It is also seen in young children/infants with abnormally weak bones e.g. rickets because of defective mineralisation of the bones by calcium necessary to harden them, thus the diaphragm which is always in tension pulls the softened bone inward. Its cause is not fully understood.

⁵⁸ ACTs provide a snapshot of how well asthma has been controlled in the preceding few weeks. It is a score out of 25. Symptoms can vary month to month, so scores can change. <https://www.asthmacontroltest.com/en-gb/welcome/>

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Penicillin V for tonsillitis. This was appropriate therapy and the twice a day 250mg dosing option⁵⁹ is in line with the BNFC.⁶⁰ In the recorded NHS 111 call made by Yusuf's mother on the evening of 15 November 2022, she says that he had been unwell for two days and had been given two doses of antibiotics by then.

- 3.7 Shortly after both assessments at the practice Yusuf's family sought further urgent medical advice. On 15 November 2022 Yusuf was seen at 12:30 in the practice and at 22:45 in the evening he went to Rotherham UECC. On 18 November 2022 Yusuf was seen at 11:20 in the practice and then at approximately 13:00 the family called 999. At 12:35 on 18 November a call to the children's ward at Rotherham Hospital was made by Yusuf's uncle seeking admission for Yusuf.
- 3.8 The records of the assessments, the interviews with the clinicians and the family's recollections show that appropriate assessments, treatment plans and safety netting advice were given based on the observations taken and his presentation at the time. Given that on each occasion further urgent medical advice was sought there would not have been an opportunity for primary care to reassess him.
- 3.9 The following issues that come from reviewing the information would not have altered the outcome for Yusuf but are observations made as part of our review.
- 3.10 At the time of the family's first call to the practice on 15 November 2022 at 08:23, while the receptionist offered a face-to-face review, it was not made clear to the family which clinician they would see (name or designation of the clinician). Providing that information would have been helpful.
- 3.11 Reviewing the notes and interviewing the primary care nurse practitioner and the locum GP show that, while their assessments, care plans and safety netting were appropriate, a small number of additional observations could have been carried out in line with best practice guidelines. We are of the view that all primary care clinicians should be encouraged to complete training and regular refresher training in assessing sick children. We have made a recommendation in relation to sharing written/accessible patient information as part of safety netting process and this applies to primary care as well as acute care.
- 3.12 We identified that whilst paediatric pulse oximeters at the practice might have been available one was not used and we understand one was broken. Measures should be taken to ensure that clinicians have access to age-appropriate equipment for their assessments of children.
- 3.13 We also identified that practitioners were not able to consistently describe the options for securing an urgent paediatric review from secondary care services. It is clear through interviews that the expectation is that very unwell children who require urgent assessment should attend the UECC, which is the correct pathway, but the primary care staff did not make it clear to Yusuf's mother that the GP could seek a paediatric opinion through this route. The children's assessment unit is for a paediatric opinion (including for GP referrals) and children would normally attend via the UECC for a prearranged meeting with a paediatric doctor. Direct admission to the ward is typically for children who have been discharged in the preceding 48 hours and need to be readmitted. However, we have seen no evidence of a written protocol for accessing advice or an admission to hospital for the general practice for children. Local pathways do not seem to be well understood with respect to seeking a paediatric opinion and admitting unwell children.
- 3.14 His family seem to have understood that the GP said he was unable to refer to paediatrics at Rotherham. The normal pathway would be that the GP refers to the paediatric registrar at the local hospital who would then agree to see the child in the UECC or paediatric assessment unit. The child then becomes the responsibility of the paediatric team who would treat with IV antibiotics if they felt that was necessary. However, both tonsillitis and pneumonia are usually treated with oral antibiotics unless the child is very unwell or cannot tolerate the oral version.

⁵⁹ It is usually given at 125mg four times a day (QDS) but can also be prescribed at 250mg twice a day (BD).

⁶⁰ British National Formulary for Children.

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- 3.15 On 18 November 2022, Yusuf's mother was concerned that her son was "*not even 1% better*" (this was recorded in her conversations with the GP practice and then again with the 999 call handler later in the day). Yusuf was given an emergency face-to-face appointment at the GP surgery, and he was prescribed erythromycin to broaden the antibiotic cover because the Penicillin V did not seem to be helping the tonsillitis. Yusuf's heart rate was 122 at that time, which is an amber flag on the NICE sepsis risk stratification chart⁶¹ which means "*moderate to high risk*". As there were no concerns about Yusuf's immunocompetence, it was appropriate to send him home with advice to go to hospital if he was no better later that day.
- 3.16 However, the absence of a respiratory rate recording, oxygen saturation levels and capillary refill times meant that a sepsis screen could not have been fully completed. The recording of these physiological observations would have been good practice but would not have made a difference to his outcome at this stage because Yusuf's mother sought urgent care within 90 minutes of leaving the GP surgery.

Rotherham NHS Foundation Trust

Commentary on this care episode and points for learning

- 3.17 Yusuf was appropriately triaged at Rotherham Hospital on 15 November 2022 according to the recorded observations. The POPS was used to assess his acuity which is the agreed protocol in use at the Trust. There is no nationally agreed PEWS in the UK although work is underway in the roll out of a standardised national PEWS.
- 3.18 The initial triage and nursing input during the night of 15 November was appropriate. However, the department was exceptionally busy and had one junior doctor absent because of sickness, this resulted in long waits. The nursing and medical team we spoke to did not feel that this was a contributory factor in Yusuf's deterioration following his visit. They were reflective but adamant at interview that nothing could have been done differently that night with his care and treatment decisions. On direct questioning, they agreed that having a paediatric registrar on site who is not covering the ward, the labour ward and the neonatal unit at the same time, would be helpful in general but is unlikely to have led to different management decisions in this case. The doctor involved was experienced in paediatric care, possibly more experienced than a junior paediatric registrar. As an advanced paediatric life support instructor, he had a very good understanding of the unwell child and of the importance of listening to parents as their advocates. We consider that on the basis of Yusuf's observations, presentation and diagnosis there was a reasonable expectation that the antibiotics prescribed were appropriate and an admission was not clinically required.
- 3.19 Yusuf had waited six hours 20 mins before having a medical review which was significantly longer than the average time that evening. (During the period under review, the Trust was one of 14 UK field test sites who were testing proposed new national urgent care standards intended to replace the current four hour A&E target. During this period the Trust was therefore not working to the national four hour standard as they were field testing the proposed new metrics⁶². This commenced 22 May 2019, with a formal Memorandum of Understanding in place between the Trust and NHS England/NHS Improvement) and is due to cease from 15 May 2023. We know from the family's account that they were told that there was only one doctor in the paediatric UECC and that after midnight, that individual was responsible for covering adults and children. The family had concerns about the way they were spoken to overnight, and we wonder if the clinical teams found communication with the family challenging. The doctor who eventually saw Yusuf is an experienced UECC doctor who would not have needed to refer to a paediatrician on the basis of Yusuf's presentation that night and would not have needed to do any further investigations or admit him. If

⁶¹ [NICE sepsis risk stratification chart \(2017\)](#)

⁶² Time to Initial Assessment, Time from Arrival to being Seen for Treatment and Mean Time in the Department. These were monitored as Mean Arrival To Initial Assessment (Minutes), Mean Arrival To Seen For Treatment (Minutes), Mean Time In Department (Minutes).

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he had seen him earlier, he would have been sent home earlier, he would not have requested an admission.

- 3.20 Yusuf's mother did have a video of the breathing pattern that concerned them but this was not shared or mentioned in the doctor's notes (despite his mother saying she tried), nor did the doctor document the verbal safety net advice given to the family. We have interviewed that doctor; he did not give the family written safety net advice and was not aware of the Healthier Together site which the Trust told us is the resource in use at Rotherham for written safety net leaflets.
- 3.21 Yusuf's clinical observations did not warrant an admission to hospital, but his mother was very worried about her child's breathing. She had taken two videos of Yusuf prior to taking him to the UECC. Whilst there is an element of speculation in this regard, videos can prove useful in assessing children and this information might have been helpful. However, his chest was clear at the time and there were no clinical signs of a chest infection or pneumonia. The first chest X-ray taken two days later at Sheffield Children's Hospital was normal and adds credibility to the normal chest assessment at Rotherham in the early hours of 16 November. Had he been admitted, Yusuf would have seen a paediatric consultant on the ward round later that day. We cannot predict if this would have made a difference to the eventual outcome in this case, although treatments were not effective once given at Sheffield.
- 3.22 The account from the nurse that night suggests that Yusuf's mother was sufficiently empowered to raise concerns with the staff while waiting to see the doctor. His uncle is described as being quite forceful in his request for his nephew to see a doctor and the staff interpreted this as both a concern for his nephew's welfare and frustration at his family members being in the department for so long overnight. There were multiple attempts by Yusuf's mother and uncle to raise their concerns but they felt they were not listened to.
- 3.23 On 18 November, Yusuf's uncle called the ward to ask if his nephew could be admitted for IV antibiotics after he had been seen by his GP. There was no formal record of the call made which lasted 10 minutes. During the call his uncle states he argued vehemently for an admission but was not listened to. Following discussions with both family and the ward nursing team it is our view that this call failed to successfully communicate to Yusuf's family the rationale for the expected pathway (via the UECC). At this stage his family lacked confidence that Yusuf would get immediate urgent attention at Rotherham Hospital. We understand that new procedures have now been implemented to make a record of telephone calls to the children's ward.
- 3.24 During our review, we noted a number of recording errors at Rotherham Hospital:
- Yusuf's height was incorrectly recorded and had probably been transferred from the records from a previous asthma clinic. This might make sense for adults but is inappropriate in paediatric care and the IT coding behind this needs to be changed to exclude people under the age of 18. Weight and height recording in children is important as medication doses are often calculated per kg and an accurate recording is essential for accurate medication prescribing.
 - BMI calculations used in the asthma clinic are more appropriate for adults; BMI centiles are more appropriate for children.
 - In one set of observations Yusuf had "*nasal cannulae*" recorded, which suggests oxygen therapy. The oxygen administration recording was an error but would not have impacted on his care.
 - The UECC doctor is a ST6, but his position comes up automatically as "*foundation doctor*" as that is what he was when he originally worked in the Trust (about six years previously). This is an IT error at Rotherham which should be corrected because it can be misleading in a clinical record that is required for investigation and legal purposes.

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Yorkshire Ambulance Service NHS Trust

Commentary on this care episode and points for learning

- 3.25 On 15 November at 22:46:38, Yusuf's mother made a call to the NHS 111 service (hosted by Yorkshire Ambulance Service NHS Trust). Following a description of his condition she was advised to attend Rotherham UECC. Her call was coherent and sensible, and she was patient with the numerous questions that the NHS 111 pathway coordinator had to ask. The call was appropriately managed by the NHS 111 call handler and was appropriately escalated to a clinician. There were no communication issues in this interaction. His family followed the advice to take Yusuf to Rotherham Hospital.
- 3.26 On 18 November at 12:59, Yusuf's mother called 999 and gave a clear description of a very unwell child with an airway and/or breathing issue. She said her son had been unwell for one week but had only had a "very little" runny nose. This made a viral infection less likely. The ambulance arrived at their house six minutes and 20 seconds after the start of her call.
- 3.27 Yusuf was found to be hypoxic (with oxygen saturations of 91% on air) with a high heart (160 on departure from the house) and high respiratory rate (32 respirations per minute). His GCS score was recorded as 15, but it did not take note that he was only responding to voice. He should have been given a score of 14.
- 3.28 The outcome of the attendance was Yusuf's appropriate transportation to Sheffield Children's Hospital, although we note that the altercation between the service and family members over the phone in relation to the destination has been subject to a separate complaint investigation. We are of the view that the additional delay caused did not impact Yusuf's eventual care.
- 3.29 To assess the care and treatment that was given we have referred to guidelines produced by the JRCALC,⁶³ often referred to as just the 'JRCALC guidelines'. The guidelines are produced for NHS ambulance service paramedics, on behalf of the Association of Ambulance Chief Executives (AACE).
- 3.30 These guidelines include a number of points that specifically relate to this case and they have been used for this review:
- febrile illness in children
 - medical emergencies in children overview
 - oxygen
- 3.31 Yusuf's documented examination indicated that he had no shortness of breath. However, his significant tachypnoea (rapid breathing) of 32 respirations per minute was documented on two occasions – this would indicate difficulty in breathing and/or shortness of breath. This statement therefore contradicts the observations obtained. We would have expected further documented examination specifically around WOB and auscultation (listening to sound in the lungs) to identify a cause for both the increased respiratory rate and the low oxygen saturations. This was important because he had been given antibiotics that day for a possible chest infection. Looking at other potential differential diagnoses such as the exacerbation of his known asthma, a chest infection/pneumonia or consolidation would have been appropriate.
- 3.32 Yusuf was also recorded as being pale. Pallor is a significant clinical finding in a child, and we would have expected there to have been a documented central capillary refill time which would have given

⁶³ [JRCALC Guidelines](#) Working closely with the National Ambulance Service Medical Directors (NASMeD) who represent all UK ambulance services, JRCALC effectively fulfils the liaison role of its title. The committee is comprised of experts ranging across the whole spectrum of medical disciplines, including paramedics, physicians, midwives, nurses, general practitioners, pharmacists, surgeons, obstetricians, pathologists and others. Members are nominated by their respective organisations /specialities /colleges and formally convene three times a year, with the majority of the guidance review and development happening between meetings.

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an overall impression of his perfusion and blood circulation. This would also have been part of an expected sepsis screen, but it was not completed.

- 3.33 It is documented that Yusuf was not able to eat and drink properly. His mother stated that he last used the toilet that morning to urinate and last opened his bowels two days ago. It is possible that Yusuf could have been dehydrated, and we would also have expected further documented examination to explore this.
- 3.34 The paramedics put Yusuf on 2L of oxygen at 13:20 as his saturations were at 91% on room air. His readings deteriorated after being taken off oxygen. The paramedics put him back on 1L of oxygen and his saturations increased again to 99%. JRCALC guidelines state that supplementary oxygen should be administered to children with significant illness and/or injury and that all children presenting with this should receive high levels. Given he presented with tachypnoea, tachycardia (rapid heart rate) and low oxygen saturations he should have received high levels of supplementary oxygen.
- 3.35 In total there were two sets of observations documented, one at 13.18 and one at 14.15. These are incomplete with the first (primary) set omitting to include a heart rate and with both sets missing the blood pressure, capillary refill time, electrocardiogram (ECG) and FeverPAIN score. A blood pressure is difficult to accurately obtain in young children pre-hospital admission and other observations (capillary refill time and colour) would have given a better and earlier overall picture of the child's perfusion status. That said, the observations that were taken were strongly suggestive of Yusuf having a significant respiratory issue.
- 3.36 While these points did not impact the ultimate decision to transfer him to hospital, the medical emergencies in children guideline states that a full set of observations should be completed. Accurate recordings are critical to decision-making and guidelines should have been adhered to.
- 3.37 During the documented examination, Yusuf presented with one red flag when assessing paediatric fever (pallor) and five amber flags:
- wakes only with prolonged stimulation
 - decreased activity
 - oxygen saturation less than 95% in air
 - tachycardia more than 140 beats per minute for ages two to five years
 - fever for more than five days
- 3.38 The JRCALC guidelines state that *"for a child with any red flags they must be conveyed to an ED with appropriate paediatric services providing an ATMIST⁶⁴ pre-alert and conveyed under emergency conditions. They should consider sepsis or meningitis as possible causes and provide care en route"*. This guidance is reflected in the Yorkshire Ambulance Service NHS Trust Assessment, Conveyance and Referral of Patients Policy (February 2020).
- 3.39 Yusuf was showing signs of both breathing and circulatory compromise. He was seriously unwell and had a time critical condition requiring transportation to the nearest suitable receiving hospital without delay and providing a pre-alert. The crew informed Yusuf's mother that he would be taken to the nearest paediatric receiving unit (which was at Rotherham Hospital) given his condition. However, at 13:38 his uncle rang 999 from work to insist that the crew took his nephew to Sheffield Children's Hospital instead. The uncle wanted the call taker to speak to the crew to give them these instructions. The call taker attempted to explain that the crew were best placed to make that decision, but his uncle was insistent that the call taker told them. The call taker put the uncle on hold then came back and said they needed to speak to the crew. It was then established that the uncle was not on scene with either the patient or the crew so the uncle stated he would speak with them.

⁶⁴ The ATMIST handover is used by emergency medical services as a rapid, accurate handover tool for a time critical patient.

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- 3.40 The uncle's request (along with his insistence about Yusuf being admitted directly to the ward at Rotherham for IV antibiotics) was understandable given the family's concerns about Yusuf's health (and their impression that there were no beds or doctors at Rotherham) but would have been at odds with national and local guidelines. Yusuf was taken to Sheffield Children's Hospital; the manner in which this request was dealt with by the ambulance crew is subject to a complaint investigation and is not within scope of this investigation.
- 3.41 We do note, however, that the paramedic crew arrived at Yusuf's house at 13:04 and the time of transfer to the ambulance was 13:48 and the leaving scene time was 14:00. This gives an overall time of 56 minutes on scene. Given his presentation, transportation to hospital without delay should have taken place and an on-scene time of 56 minutes could be considered excessive. However, it is likely that the discussion between the family and paramedics in relation to the proposed destination hospital increased the intervention time.
- 3.42 The nearest most appropriate hospital with paediatric services was Rotherham Hospital, which from the incident location (Yusuf's home) was 2.7 miles away with an estimated travel time of 10 minutes. The family insisted Yusuf was conveyed to Sheffield Children's Hospital which was 10 miles away with an estimated travel time of 20 minutes.⁶⁵

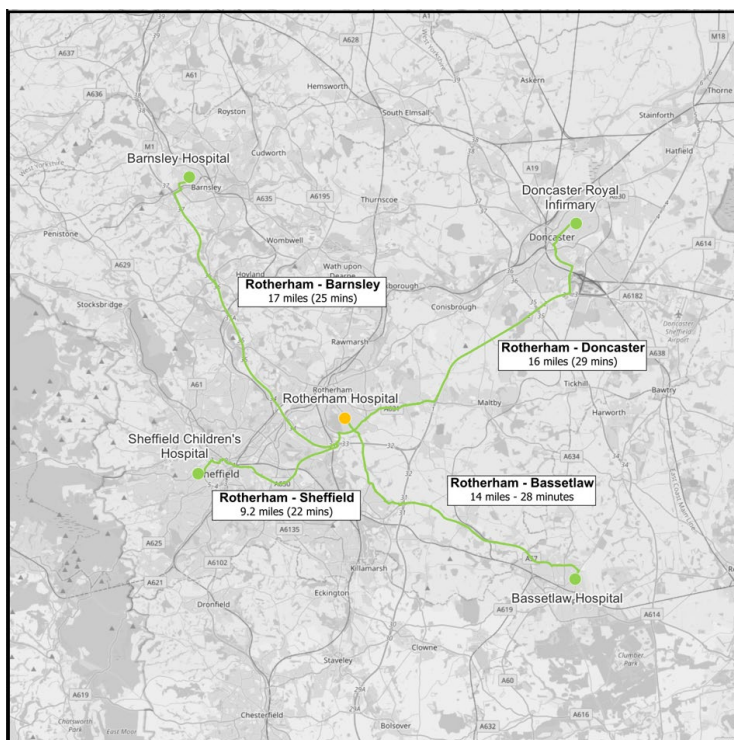


Figure 1: The above map shows distances to local hospitals in relation to Rotherham.

- 3.43 There was no clinical need for the ambulance to have bypassed Rotherham and this would have been an appropriate hospital for Yusuf to have been taken to with his presentation at that time. JRCALC guidelines support a pre-alert to the receiving hospital, but we can find no record of this happening. However, its absence did not impact Yusuf, who was triaged on arrival at the hospital.

Conclusions/learning

- 3.44 The paramedic records lack documented essential examinations and physiological observations for Yusuf considering his history and presentation to the ambulance crew. Omissions include: first heart rate, capillary refill time, respiratory examination including WOB and auscultation, and hydration status. They had a working diagnosis of tonsillitis but apart from the history there is no evidence of

⁶⁵ Estimates and data from Google Maps.

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an examination that would have supported this conclusion. There is no evidence that other potential diagnoses were considered, such as a respiratory cause or dehydration. The transportation of Yusuf to hospital was, however, appropriate. Further examination by the crew would not have altered this decision but may have identified other differential diagnoses needing treatment.

- 3.45 The administration of oxygen was not in line with national guidance, although there is evidence that the amount given did have a positive effect on the Yusuf's condition.
- 3.46 The length of time the ambulance spent on scene given Yusuf's presenting condition was longer than expected but some of this time was due to discussions with the family about the hospital destination.
- 3.47 A pre-alert to the receiving hospital was indicated but did not take place. Yusuf's triage time at the ED was not impacted by the absence of this call.
- 3.48 Transport to the nearest hospital (Rotherham) under emergency conditions was indicated given the clinical findings but did not take place because of a request by the family for the ambulance to take Yusuf to Sheffield Children's Hospital. This was appropriate in the circumstances described and there is no evidence that this impacted the care that Yusuf received on arrival at the ED.

Sheffield Children's NHS Foundation Trust

Commentary on this care episode and points for learning

- 3.49 At Sheffield Children's Hospital, Yusuf was seen by three different clinical teams in the ED in an efficient manner. He was described as "*unwell, but not septic*" and the blood test results and observations back up that clinical description. All significant abnormal results were picked up, appropriately escalated and acted on and the decision-making also seems to have been appropriate. He was seen the following morning by the paediatric medical consultant as per national guidelines on admitted children.⁶⁶ He appeared to be beginning to get better. The family have a photo during this admission of Yusuf smiling a little while colouring in a book.
- 3.50 On admission to Ward 4 a nursing assessment was undertaken. This was completed in full, but we note the following in relation to his care:

The assessment noted that Yusuf had "*reduced intake*" but we can see no evidence of this being fully explained in the nursing records (for example, for how long) or of a Screening Tool for the Assessment of Malnutrition in Paediatrics (STAMP)⁶⁷ being completed. There was also no care plan or food chart to help with monitoring. Yusuf's weight was recorded as 15.8kg but his height was left blank, which would have made it impossible to complete the STAMP or calculate a BMI centile. If the score had been calculated, it is likely that Yusuf would have been classed as high risk of malnutrition due to his presenting condition and recently decreased/poor nutritional intake. As Yusuf's weight was recorded as 16.7kg when he attended Rotherham Hospital there had been a weight loss of 0.9kg in three days. His last recorded weight when he was well was 17.4kg (so there had been a total body weight loss of 9%). The high risk rating should have been responded to (i.e. action should have been taken; a referral made to a dietitian, nutritional support team or consultant; with monitoring as per an agreed care plan). Optimal nutrition was relevant to Yusuf as it is known that malnutrition can make a child more susceptible to infection and can increase fatigue. Conversely, infection also contributes to malnutrition and hence it was important for staff to fully understand his risks so that any deficiencies could be addressed.
- 3.51 A fluid balance chart was appropriately started; however, this was poorly completed over the period of his stay (some, but not all, of his food intake was also included which was inappropriate for this form). Urine output was recorded as "*passed urine*" rather than including a volume. The volumes of

⁶⁶ RCPCH (revised 2015) [Facing the Future: Standards for Acute General Paediatric Services](#)

⁶⁷ STAMP is a validated nutrition screening tool for use with hospitalised children from 2 weeks to 16 years of age <https://www.stampscreeningtool.org/>

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fluid taken orally included “sips”. IV fluids were started on admission and stopped at 13:00 on 19 November but restarted at 17:00 on 20 November. Between these times, the fluid intake and output volumes for Yusuf are unclear.

- 3.52 The fluid balance chart includes a VIP score,⁶⁸ which nurses are required to complete when attending to their patients. VIP scores were entered on the morning of the 19 November (as “0 – IV site healthy”) but there is no recorded entry after this time, despite Yusuf continuing to receive IV antibiotics which were essential to his recovery. This is a concern given that the cannula was bandaged (to keep secure) with commentary in the progress notes at 01:45 and 05:15 on 19 November that it was “very positional”. This meant its patency was intermittently affected. A change of cannula was required at 13:00 on 20 November and this meant that the administration of his lunchtime dose of antibiotics was delayed because he was not recannulated until 15:00, despite him being unwell at that point (“very unsettled, coughing lots and a prominent stridor”). An IV cannula care plan was listed as being required, but we can see no evidence of this being completed. The family have photographic evidence of fluid leakages over the weekend, and it is recorded in the nursing notes that at 06:30 on 21 November, the bandage was covered in blood as the cannula port was loose.
- 3.53 There were concerns over the weekend that Yusuf might not have got the prescribed antibiotic dose. However, benzylpenicillin was given QDS and it is unlikely that the leaking cannula would have significantly affected the antibiotic efficacy overall⁶⁹.
- 3.54 Throughout the progress notes, there is reference to Yusuf being in pain but with no qualification about where this pain was or how severe it was. Analgesia appears to have been given with good effect, but we have seen no evidence of a care plan or pain assessment tool being used to quantify the pain that was being experienced.
- 3.55 In Sheffield, one version of the early warning observation scoring is used in the ED (POPS) and a different version (PEWS) is used on the ward. This does not strike us as sensible practice, although we do not believe that this impacted on Yusuf’s care.
- 3.56 Yusuf started to become much more unwell on the morning of Monday 21 November. The observations chart shows a sudden increase in his heart rate at around 09:00 and the clinical notes describe a child with a worsening airway and breathing problem. The family’s videos show a child struggling to breathe. This would be unusual for a child who had seemed to be getting better unless he had acute bronchospasm⁷⁰ for some reason.
- 3.57 Yusuf was found to have a “tight chest” and was treated with salbutamol – bearing in mind his history of asthma – but with very little positive effect. His tonsils were thought to be obstructing his airway and there was talk of doing a “hot” tonsillectomy, which means removing the tonsils while they are still inflamed. His breathing responded temporarily to aminophylline but then deteriorated again. He did not tolerate high-flow oxygen on the PICU and the decision was made to intubate him.
- 3.58 Intubation was much easier than anyone expected and there was no significant airway obstruction necessitating a hot tonsillectomy. The primary problem was now seen to be in his lungs. The x-ray appearance became worse each day, the increasing consolidation correlating with the difficulty the intensivists were having with oxygenating him. He was on a large amount of oxygen compared to

⁶⁸ The VIP score is used for the assessment of the early signs of phlebitis, along with the prompt removal of peripheral IV cannulas.

⁶⁹ Antibiotics should ideally be given at regular intervals. In sepsis, the timing of the first dose of antibiotics is important <https://ccforum.biomedcentral.com/articles/10.1186/s13054-021-03883-0> and UK national guidance is that they be given in the first hour. However, once started on antibiotics, there is little evidence that missing a dose matters. NHS advice is that, if missed, the dose should be taken as soon as the patient remembers or, if it’s almost time for the next dose, skip the missed dose <https://www.nhs.uk/conditions/antibiotics/>. A 2019 study on missed intravenous antibiotic doses in an intensive care setting in hospital found that only 8% of the patients had all their antibiotic doses given within an hour each side of the prescribed time. Missed doses in this study were associated with an increased length of stay but not with increased mortality.

⁷⁰ Bronchospasms are the tightening of the muscles that line the airways in the lungs.

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when he was initially intubated and he did not respond definitively to any changes in ventilation or position, any new antibiotics, antifungals, antivirals or any chest physiotherapy.

- 3.59 Yusuf had a leukemoid reaction, which means the bone marrow pushes out large numbers of white cells as part of a non-cancerous inflammatory reaction, usually an overwhelming infection, massive trauma or a paraneoplastic process.⁷¹
- 3.60 There was good engagement by a range of healthcare professionals throughout his case, as shown in the medical notes, with attention paid to possible other causes of his deterioration, including Lemierre's syndrome.
- 3.61 The hypoxia inevitably led to multi-organ failure and DIC⁷² and Yusuf had a cardiac arrest two days after his admission to the PICU. The team discussed in their mortality meeting whether Yusuf should have been referred earlier for ECMO – they concluded that, given the criteria for referral, the team had referred at the earliest opportunity (based on his oxygenation index).
- 3.62 We interviewed four PICU consultants who had been involved in his care. All had been surprised that he died. The consultants had considered other diagnoses, including diphtheria, pertussis (whooping cough) and haemophilus influenzae B (Yusuf was not immunised against any of these) and had worked hard to try to halt whatever process was leading to his unexpected deterioration. They explained that they had discussed leukapheresis as a management for his extremely high WCC, but mortality from a leukemoid reaction is very high and the evidence behind trying to reduce the white cells by exchange transfusion is not strong. He was being discussed for ECMO when he died and none of the team felt that he could have been referred earlier as the threshold for ECMO had only just been reached on 23 November. They felt that his chest pathology was not typical for an infective pneumonia, and they did not believe that earlier IV antibiotics would have made a difference.
- 3.63 Until the last few days of his life, there was no significant rise in any of Yusuf's inflammatory markers (CRP, erythrocyte sedimentation rate (ESR)), no rise in lactate and no particularly abnormal vital signs. This was not a usual presentation of sepsis⁷³ or pneumonia.
- 3.64 On 21 November a radiologist questioned whether the X-ray findings were consistent with Lemierre's syndrome. This is a rare condition characterised by inflammation and clots in the internal jugular vein and blood infection caused by primarily anaerobic organisms following a recent throat infection. It is usually found in young, previously healthy adults and children. Lemierre's syndrome should be suspected in young healthy patients with prolonged symptoms of pharyngitis⁷⁴ followed by symptoms of septicaemia⁷⁵ or pneumonia, or an atypical lateral neck pain. Diagnosis requires two out of three of the following:
- 1) identification of thrombophlebitis of the internal jugular vein by ultrasound scan, or perhaps more reliably, by CT scan
 - 2) growth of *Fusobacterium necrophorum* anaerobic bacteria on a blood culture⁷⁶
 - 3) seeding to the lung causing a pneumonia like picture
- 3.65 Yusuf was on a considerable amount of treatment that would have treated the bacteria that causes Lemierre's syndrome (*Fusobacterium necrophorum*) as well as the more common streptococcus A.

⁷¹ Symptoms that may develop when substances released by some cancer cells disrupt the normal functioning of surrounding cells and tissues.

⁷² DIC is a rare but serious condition that causes abnormal blood clotting throughout the body's blood vessels. DIC may develop if there is an infection or injury that affects the body's normal blood clotting process.

⁷³ Amarnani, S. and Ranjan, A. (2022) [Lemierre's Syndrome: A lethal Complication of Acute Tonsillitis](#)

⁷⁴ Inflammation of the pharynx, causing a sore throat.

⁷⁵ Blood poisoning, especially that caused by bacteria or their toxins.

⁷⁶ Eilbert, W and Singla, N. (2013) [Lemierre's Syndrome](#)

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- 3.66 Yusuf's blood cultures were negative but were only aerobic cultures⁷⁷ so would not have picked up *Fusobacterium necrophorum*.⁷⁸ The doppler ultrasound scan of his neck on 22 November at 11:44am did not show any inflammation or clot formation consistent with Lemierre's syndrome. An ultrasound of his chest was done at the same time, and it showed "*dense consolidation in the right upper lung*". This may be what his family understand by his neck being "*blocked*". A CT scan would have been helpful in ruling out blood vessel involvement, but he was not stable enough to go to the CT scanner.
- 3.67 Yusuf did have the third diagnostic feature of a pneumonia like picture. He had low platelets, which is seen in Lemierre's syndrome, but it is also sometimes seen in fungal illnesses. He was on an antifungal. He was on Tamiflu in case the negative influenza swab was a false negative. Numerous samples were sent to the laboratory, including secretions from his endotracheal tube on 21 November, and everything returned normal.
- 3.68 Yusuf had a blood film sent to the haematology laboratory and it was reported as "*neutrophilia*" and having "*platelets in clumps*". There was no time for investigations such as a CT scan, bronchoscopy or bone marrow biopsy which may have helped with establishing a diagnosis.
- 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.

⁷⁷ It would be normal not to take anaerobic cultures.

⁷⁸ Nygren, D. and Holm, K. (2019) [Invasive Infections with *Fusobacterium Necrophorum* Including Lemierre's Syndrome](#)

Appendix 1 – Terms of reference

Terms of reference for independent investigations in accordance with Appendix 3 of NHS England's Serious Incident Framework 2015

The following terms of reference for an independent review into the care and treatment of Yusuf (2022/25466) have been drafted by NHS England North East and Yorkshire, in consultation with South Yorkshire Integrated Care Board.

The terms of reference will be developed further in collaboration with the appointed investigative supplier, Yusuf's parents and his family.

Purpose and scope of the investigation/commission

To review Yusuf's whole care pathway from his first contact with health services on 15 November 2022 (which includes contact with the general practitioner, Yorkshire Ambulance Service, Rotherham NHS Foundation Trust and Sheffield Children's NHS Foundation Trust), to promptly establish the facts on which clinical decisions were based and determine whether there are any lessons to be learned from the case in relation to the provision of and access to emergency and inpatient paediatric care.

To identify any areas of best practice, opportunities for sustainable system learning and areas where improvements are required.

Family and staff involvement

- Ensure that the family and relevant staff are fully informed of the investigation and the investigative process and they understand how they can contribute to the process.
- Ensure that staff contributing to the investigation process understand how their information will be used and processed and are aware of organisational support.

Terms of reference

- Building on the rapid review of the case, compile a detailed chronology/timeline leading to hospital admission – mapping key events and decision-making.
- Consider the response immediately following the incident to identify and implement any immediate learning.
- Undertake a desk top review of each contact and consider if the care was appropriate at the time of presentation
- Consider whether any system and/or environmental factors impacted on decision-making across all health contacts, benchmarking against national standards for the care of children in emergency care settings and the use of paediatric early warning tools.
- Were there any points where Yusuf needed an admission paediatric bed? If that was the case, determine the availability of paediatric inpatient beds and access to paediatric expertise (medical and nursing) and the extent to which, if at all, these factors impacted on decisions taken in respect of Yusuf's care.
- Review how paediatric bed capacity is managed in The Rotherham NHS Foundation Trust and how the escalation process works in South Yorkshire should capacity be limited.
- Determine whether the concerns and accounts of Yusuf's family, including his parents and uncle, in respect of his presentation were fully considered as part of care planning.
- Consider whether Yusuf's presentation was fully recognised and understood by healthcare professionals, commenting on whether appropriate care, treatment and support to the family were offered, identifying both areas of good practice and areas of learning.

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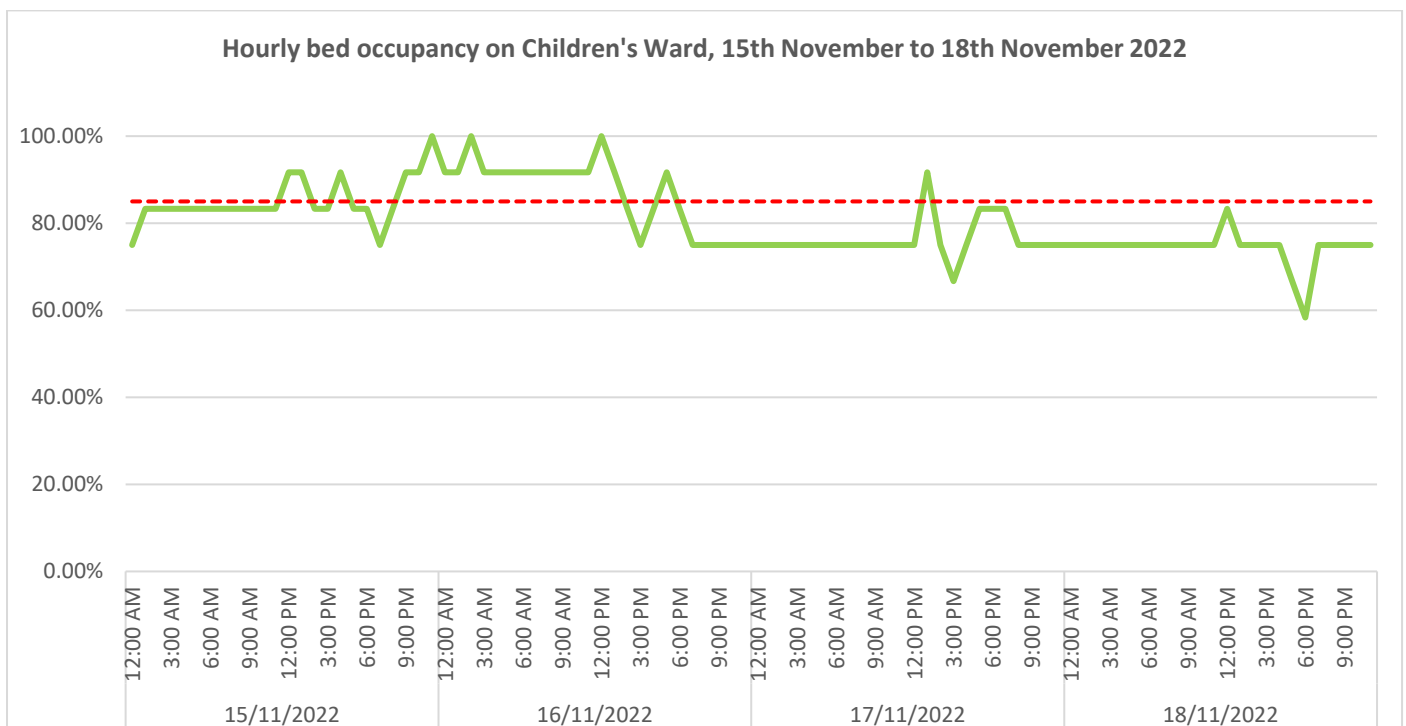
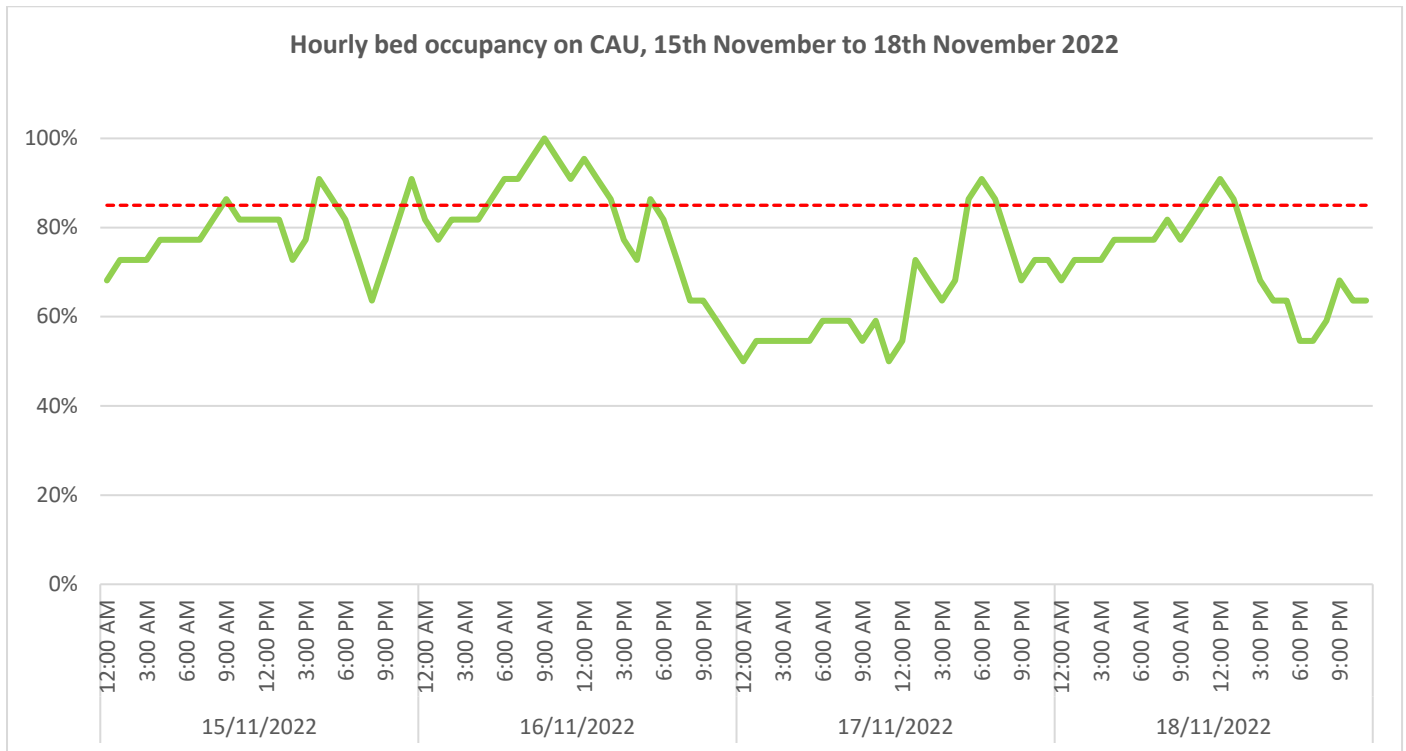
- Identify whether health professionals involved in Yusuf's care had the relevant training or knowledge (e.g. spotting the sick child/PEWS/POPS).
- Determine whether the timeliness and interpretation of diagnostic tests impacted on care and treatment decisions.
- Determine how NHS paediatric services should respond effectively if similar circumstances were to occur.

Deliverables

- To ensure continuous learning, promptly communicate any opportunities for early learning identified throughout investigative activity to the relevant health organisation.
- Provide NHS England with a monthly update on progress (template to be provided by NHS England) detailing actions taken, actions planned, family contact and any barriers/risks to the Review's progress.
- Based on investigative findings, make organisational or service specific, outcome-focused recommendations, with a focus on sustainable system improvement, with a priority rating and expected timescale for completion.
- Provide a final written report and a separate, anonymised and publishable Executive Summary to NHS England (that is easy to read and meets NHS England accessible information standards) within two months of receipt of all clinical records.
- Share the findings of the report in an agreed format, with Yusuf's parents and family, seek their comments and ensure appropriate support is in place for receiving the findings, ahead of publication by NHS England.
- Where recommendations are made, contribute to a stakeholder meeting hosted by NHS England, to provide an opportunity for organisations to explore and fully understand the intention behind all recommendations (to assist effective action planning) and to make any appropriate revisions to the recommendations based upon discussions.

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Appendix 2 – Bed capacity on CAU and children's ward (Rotherham) 15-18 November 2022



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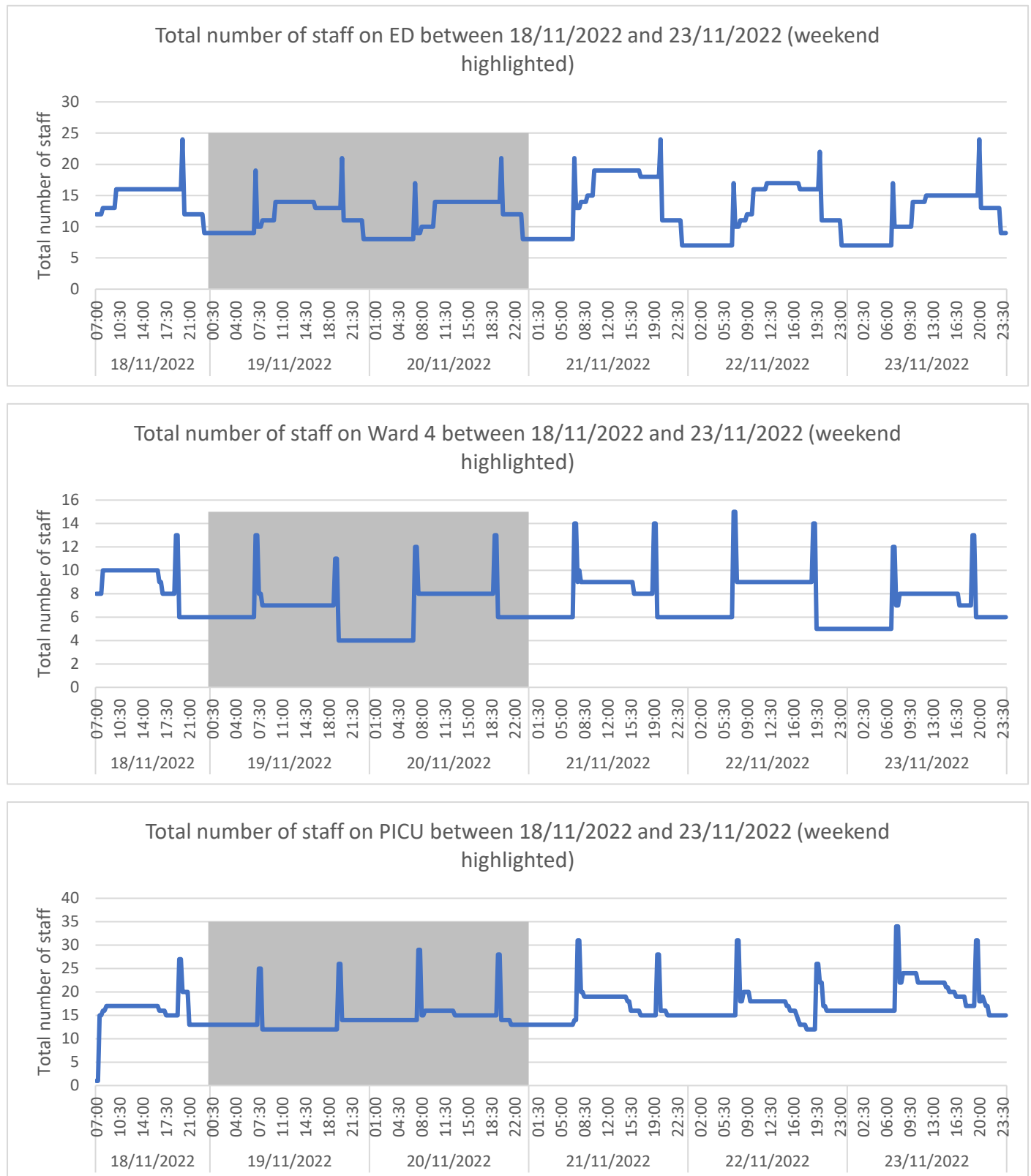
Appendix 3 – Test results 18 to 23 November 2022

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Appendix 4 – Ward staffing levels at Sheffield Children’s Hospital

We analysed staffing levels at Sheffield Children’s in the ED, Ward 4 and on PICU. We did not identify any specific shortfalls. The grey area is the weekend period of 19/20 November 2022.



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Appendix 5 – Glossary of terms used

AACE	Association of Ambulance Chief Executives
ACT	asthma control test
AKI	acute kidney injury
BD	twice a day (prescription)
CMV	cytomegalovirus
COPD	chronic obstructive pulmonary disease
CRP	C-reactive protein
CT	computerised tomography
DIC	disseminated intravascular coagulation
EBV	Epstein-Barr virus
ECG	electrocardiogram
ECMO	extracorporeal membrane oxygenation
ED	emergency department
eGFR	estimated glomerular filtration rate
ENT	ear, nose and throat
ESR	erythrocyte sedimentation rate
EWS	Early Warning Score
GCS	Glasgow Coma Scale
Hb	haemoglobin
HFOV	high-frequency oscillatory ventilation
ICU	intensive care unit
Ig	immunoglobulin
IV	intravenous
JAR	joint agency review
JRCALC	Joint Royal Colleges Ambulance Liaison Committee
L	litre
NASMeD	National Ambulance Service Medical Directors
PCR	polymerase chain reaction
PEWS	Paediatric Early Warning Scoring
PICU	paediatric intensive care unit
POPS	Paediatric Observation Priority Score
PRN	as required (prescription)
QDS	four times a day (prescription)
RCPCH	Royal College of Paediatrics and Child Health
SIRS	systemic inflammatory response syndrome
TDS	three times a day (prescription)
UECC	urgent & emergency care centre
VIP	visual infusion phlebitis
WCC	white cell count
WOB	work of breathing

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