MR G IRVINE
SENIOR CORONER
EAST LONDON
Walthamstow Coroner's Court, Queens Road Walthamstow, E17 8QP
[redacted]

REGULATION 28: REPORT TO PREVENT FUTURE DEATHS (1)

[redacted]

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. [redacted] Chief Nursing Officer, South East London ICB** [redacted] **2. [redacted] Chief Executive Officer, South-East London Integrated Care System** [redacted]
1	**CORONER** I am Graeme Irvine, senior coroner, for the coroner area of East London
2	**CORONER'S LEGAL POWERS** I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013. http://www.legislation.gov.uk/ukpga/2009/25/schedule/5/paragraph/7 http://www.legislation.gov.uk/uksi/2013/1629/part/7/made
3	**INVESTIGATION and INQUEST** On 24th September 2024, this Court commenced an investigation into the death of Kwabena Amoateng aged 17 years. Following an autopsy Kwabena's medical cause of death was determined as; *"1a Multiple organ failure* *1b Severe acute respiratory distress syndrome* *1c Acute negative pressure pulmonary oedema* *1d Congenital Hypoventilation Syndrome, Upper airway obstruction.* *II Primary pulmonary hypertension, hyaline membrane disease, lobar pneumonia"*

	An inquest was opened on 08/01/2025 which concluded on 4th July 2025 after a one-day hearing The Inquest resulted in a narrative conclusion. *Narrative conclusion:* *Kwabena Amoateng died in hospital on 23rd September 2024.* *Kwabena was a 17yr old boy who suffered from congenital central hypoventilation syndrome ('CCHS') a condition that impeded his ability to regulate his own breathing. Kwabena was treated with non-invasive ventilation.* *On 16th September 2024 Kwabena developed gastrointestinal symptoms consistent with an infection. Infections are known to exacerbate the symptoms of CCHS and properly, his mother escalated her concerns to Kwabena's doctors.* *On 18th September 2024 Kwabena's mother called 111 who sent an ambulance to assess her son. The ambulance crew referred Kwabena for GP assessment as he was not found to be critically unwell or in need of hospital based treatment. Later that night, as no out of hours GP service was available for a child, Kwabena's mother called 111 again, a second ambulance attended in the early hours of 19th September 2024 and although Kwabena's symptoms had developed he was not deemed to be critically unwell, was not assessed to be conveyed to hospital and was referred for GP care.* *A Paediatric Respiratory Action Plan ('PRAP') had been produced by Kwabena's specialist doctors to inform healthcare professionals on how to treat his complex condition in the event of an emergency. That document was not available to paramedics who assessed him on 18th or 19th September 2024. Had the PRAP been available, it is probable that Kwabena would have been escalated for hospital admission.* *On the evening of the 21st September 2024 Kwabena became unwell whilst eating, he collapsed. CPR was commenced by his parents and 999 was called. An ambulance attended promptly and experienced significant difficulty in managing his airway. Kwabena was transported to hospital where he was diagnosed with aspiration pneumonia.* *At hospital Kwabena suffered a cardiac arrest, he was resuscitated and transferred to intensive care. There, despite maximal treatment he developed acute respiratory distress syndrome and died on 23rd September 2024."*
ourt	**CIRCUMSTANCES OF THE DEATH** Kwabena Amoateng, a 17 yr old boy died in hospital on 23rd September 2024. Kwabena suffered from congenital central hypoventilation syndrome ('CCHS'). Kwabena fell ill on 16th September 2024, numerous contacts occurred with healthcare professionals over the next 5 days, including his GP, the 111 service, and the London Ambulance Service. It was not until the 21st September 2024 that he was eventually taken to hospital by ambulance where he subsequently died on 23rd September 2024.
5	**<u>CORONER'S CONCERNS</u>** During the course of the inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths could occur unless action is taken. In the circumstances it is my statutory duty to report to you. The **MATTERS OF CONCERN** are as follows. –

	1. The inquest found that a critically important document had been produced by his specialist respiratory doctors to assist emergency healthcare professionals in understanding his rare and potentially dangerous condition - CCHS. The document, A Paediatric Respiratory Action Plan ('PRAP') set out the necessary steps to be considered should Kwabena fall ill. 2. During Kwabena's final illness, those assessing him from 16th-21st September 2024 were unaware of this vital document as it had been mislabelled and misfiled within the online records available to them. 3. Had the PRAP been more prominently filed it is likely that those assessing Kwabena would have escalated his treatment to admission to hospital far earlier, which may have resulted in Kwabena's life being saved. 4. An investigation into why the PRAP was not visible to emergency services in this case has highlighted that there is no coordinated process to ensure a consistent approach in producing and storing such documents in online clinical records.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe you [AND/OR your organisation] have the power to take such action.
7	**YOUR RESPONSE** You are under a duty to respond to this report within 56 days of the date of this report, namely by **14th November 2025**. I, the coroner, may extend the period. Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise, you must explain why no action is proposed.
8	**COPIES and PUBLICATION** I have sent a copy of my report to the Chief Coroner and to the following Interested Persons the family of Kwabena Amoateng, CDOP. I have also sent it to the local Director of Public Health who may find it useful or of interest. I am also under a duty to send a copy of your response to the Chief Coroner and all interested persons who in my opinion should receive it. I may also send a copy of your response to any other person who I believe may find it useful or of interest. The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it useful or of interest. You may make representations to me, the coroner, at the time of your response, about the release or the publication of your response.
9	**[DATE] 18 September 2025 [SIGNED BY CORONER]** [redacted]