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**Private & Confidential**

Mr Graeme Irvine  
Senior Coroner  
Coroner Area East London  
Walthamstow Coroner's Court,  
Queens Road,  
Walthamstow,  
E17 8QP

[www.bartshealth.nhs.uk](http://www.bartshealth.nhs.uk)

Dear Mr Irvine,

**Re: Regulation 28 Prevention of Future Deaths Report: Urielle Mayila Kuyenga, Ref 25568375**

I write in response to the inquest dated 30<sup>th</sup> September 2025 and the Regulation 28, Prevention of Future Deaths report to the trust dated 9<sup>th</sup> December 2025.

We are very sorry that Miss Urielle Mayila Kuyenga died of sepsis resulting from a bacterial pneumonia on a background of Sickle Cell Disease (SCD) at only 4 years old. Since the time of her death in December 2023 the paediatric clinical haematology service at the Royal London Hospital, as the Haemoglobinopathy Coordinating Centre (HCC) for the region, have discussed events in a number of forums to surface opportunities for learning and they have taken a number of actions to improve the coordination of care for this vulnerable patient group across the system. As our response to your Regulation 28 Prevention of Future Deaths Report, I will summarise these actions now.

**Support and education for families**

In 2025, the Haemoglobinopathy Coordinating Centre (HCC) designed a website with information to support families. Whilst still in the development stage, it is planned that this website will include a range of information including about the centres in the region, clinical information about SCD and thalassemia as well as providing signposting to a range of organisations who can help and provide support to patients and their families.

To ensure the service meets the needs of its patients, a patient representative feeds into the service meetings to provide feedback from service users and to help further shape the information and service that the team provide.



### **Support primary care with education and training**

An HCC education lead has been appointed for the network. This individual is now producing a newsletter for communicating important messages across the network the team covers.

A series of educational webinars have been held to define the role of GPs in managing acute complications of SCD and for health maintenance in primary care. This includes written information, pathways for referral/ advice and awareness of the roll-out of the Universal Care Plan (UCP) in SCD. The UCP is a tool that supports patients, their families and their clinical team to co-create a personalised plan for managing the patient's care and are increasingly used for a variety of long-term conditions. In the context of patients with SCD, the team are using them to capture regular medications. For communications regarding medications to be prescribed and expectations for GPs, these are communicated through the clinic letters sent following clinical review which the team have strengthened.

This is further supported by a programme of work being led by the RLH Deputy Chief Executive Officer aimed at improving digital communications between the trust, our patients and primary care. Once implemented, the communication platform will strengthen how patients and healthcare professionals can communicate and share information through digital channels.

On 2nd July 2024, an HCC Clinical Lead alongside a Consultant in Paediatric Infectious Diseases and Immunology have delivered a GP awareness campaign including a London-wide GP webinar on the UCP. It is important to note that a UCP is not a shared care agreement and is used as guidance for clinicians involved in care. They are accessible through electronic portals for healthcare professionals in line with patients' medical confidentiality.

As part of the educational webinars the service has provided to primary care teams, sessions have also been provided to increase the general awareness around the risk of infection. This has included the benefits of the use of penicillin V in sickle cell disease (SCD) in the under 5's, pathways for escalating for clinical assessment and the need for management with intravenous antibiotics. All the webinars remain available on the North-East London (NEL) training hub, they were highlighted at the NEL Babies, Children and Young People (BCYP) delivery group in December 2025 and have been added to the NEL BCYP newsletter.

These campaigns were discussed at the National Haemoglobinopathy Panel in November 2025 to raise the awareness of it within specialist teams. Following this, a national webinar is now scheduled for 28<sup>th</sup> January 2026, led by the UK Forum on Haemoglobin Disorders.

### **Information sharing**

The service has created a generic letter template to standardise the information that is sent to parents, GPs, community teams and local hospitals. This has been in place since September 2025 and clarify the medications that are prescribed in secondary care (hospitals) and which are to be prescribed by primary care (GPs), including the prescription of prophylactic antibiotics as per the clinical guidelines. These are reiterated in the clinic letters after every clinical encounter. Additionally, once the digital

platform is implemented, this will further support the timely sharing of clinical documentation and information.

In November 2025, Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT) joined the Oracle Millennium system that Barts Health NHS Trust uses for its electronic patient record system. This means that health data and treatment plans for patients in NEL are now easier for clinicians to access and for the first time, the hospitals have a common electronic patient record (EPR). Clinicians are now able to share details of any patients that need to be transferred between any of the seven hospitals run by the two Trusts. With additional links to the East London Patient Record, a summary view of real-time clinical information is now available to GP systems across London.

### **Sickle cell guidance and pathways**

As of December 2025, 90% of children with SCD are now on a UCP. Each one will include specific and personalised information about a patient's needs, how to manage symptoms during a crisis and informed decision-making during episodes of urgent care. They also contain information on ambulance directives to avoid delays and to ensure patients are directed to the correct service in a timely fashion.

Multi-organisational work has taken place to produce SCD guidance. This includes system flagging, the development of pathways and the GP awareness campaign already described. This has been completed with the support of the London Sickle Cell Improvement Board and has involved all the boroughs overseen by NEL Integrated Care Board (ICB), the Royal London Hospital (RLH), the Partnership of East London Cooperatives (PELC), North-East London Foundation Trust (NELFT), Hackney borough and Barking, Havering and Redbridge University Trust (BHRUT).

As part of the webinars on SCD, the GP escalation pathway has been updated to include sepsis. The GP training leads in the region have been contacted to support the adoption of this locally.

Across the network, the ACT NOW (Analgesia, Compassion, Test & triggers, Notify, Oxygen, Watch) sickle cell acronym has been adopted to ensure rapid and effective response to sickle cell emergencies in hospital.

### **Governance and quality improvement**

An HCC governance lead has been appointed to lead on network wide quality improvement and governance. All serious events are discussed in the network morbidity and mortality meetings and learning points summarised in a quarterly newsletter.

A tri-borough audit of transfers of case has been undertaken in December 2025 relating to Specialist Haemoglobinopathy Team (SHT) to SHT, Local Haemoglobinopathy Team (LHT) to LHT and community to community. Following this the standard operating procedure has been updated.

### **Cultural competency & public health support**

The partnership is continuing to promote training around cultural competency to reduce stigma around health conditions. This follows "Think Family" which promotes the importance of a whole-family

approach built on the principles of reaching out and working together across health and social care to consider the needs of the individual in the context of their relationship and their environment.

For information, the Sickle Cell Society has also been looking at supporting patients with these aspects as well as leading on Public Health initiatives to address factors such as stigma.

In March 2026, the team are involved in an exhibition called 'Memory & History of Sickle Cell Disease in the UK 1950-2020'. It is due to open at RLH in March 2026 and the purpose of bringing the exhibition to RLH is to understand if, through the medium of art and storytelling, we can effect a change in staff attitude and behaviour towards our patients. The clinical team intend to use this as an opportunity to challenge staff to consider their own legacy in the history of SCD in East London.

I hope this provides you with the assurance that we have taken the events in Miss Kuyenga's care very seriously but I would be very happy to discuss or clarify any of the above points if you wished.

Yours sincerely

REPORT SIGNATURE

  
**Chief Medical Officer**  
