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Our ref:

HM Coroner Alison Mutch Coroner's Court, 1 Mount Tabor Street, Stockport SK1 3AG

By email: manchestersouthcoroners@stockport.gov.uk

18 August 2025

Dear Ms Mutch,

Thank you for the Regulation 28 report of 9th May 2025 sent to the Secretary of State for Health and Social Care about the death of Master Jake Samuel Lawler. I am replying as the Minister with responsibility for Secondary Care.

Firstly, I would like to say how saddened I was to read of the circumstances of Master Lawler's death, and I offer my sincere condolences to his family and loved ones. The circumstances your report describes are very concerning and I am grateful to you for bringing these matters to my attention.

The report raises concerns over 12 lead electrocardiogram (ECG) readings being frequently misunderstood; a lack of clear national guidance for paediatric exercise induced syncope; difficulties with the national asthma scoring system at facilitating scoring for exercise induced asthma and therefore potentially masking differential diagnoses; and difficulty giving ECGs to children and young people in community care settings.

In preparing this response, my officials have made enquiries with NHS England (NHSE) to ensure we adequately address your concerns.

I note your concerns about training and national guidance. Individual NHS Trusts and other employers are responsible for ensuring that staff are, and remain, competent and capable in their area of practice. We would expect NHS Trusts and other relevant organisations to ensure that their protocols are appropriate in the wake of the death of Master Lawler. I note that Manchester University NHS Foundation Trust has considered how to improve both training and guidance as part of their Safety Improvement Plan, which they have shared with NHSE.

NHSE have noted and welcomed the actions for improvement being undertaken by the Trust in response to this matter, as do we as a Department. These include, but are not limited to:

- Ensuring that the North West Congenital Heart Disease Operational Delivery Network's (NWCHDN's) <u>Paediatric Cardiology Outpatient Referral Guidelines</u> are shared with all Clinical Group Emergency Departments (EDs);
- A review of the referral guidelines to consider the development of an addendum specific to the Trust's EDs, with a clear pathway for referral to paediatric cardiology;
- Development of a Paediatric ECG E-learning with a focus on risk stratification and the assessment and management of syncope;
- Development of teaching slides to include all cardiac causes of exertional syncope;
- Consideration of how the Trust's Electronic Patient Record system (HIVE) can alert staff to red flag signs and symptoms, with a list of abnormal paediatric ECGs that could indicate a more serious cardiac condition;
- Development of a new Standard Operating Procedure for the review of adult and paediatric ECGs across the Trust;
- Consideration of a new Patient Safety Priority to support reduction in the number of abnormal ECGs.

When my officials discussed the matter with NHSE they agreed that the misinterpretation of ECG findings is unfortunately not uncommon, and this is especially true in children. Children should therefore have ECG interpretations carried out by an expert clinician who has been trained in interpretation in the young, preferably from a congenital heart disease background.

NHSE colleagues also confirmed that they view certain skills as key parts of medical practice. This includes recognising the importance of exertional syncope and what the required next steps are, and the differential diagnoses for breathlessness. Further information can be found at the following links <a href="Causes | Background information | Blackouts and syncope | CKS | NICE; Recommendations | Asthma: diagnosis, monitoring and chronic asthma management (BTS, NICE, SIGN) | Guidance | NICE.

Regarding your concerns about a lack of professional curiosity and a holistic view of Master Lawler's care, NHSE has been engaging with the family of Jess Brady who have been campaigning on similar issues.

Jess Brady died at the age of 27 of cancer on 20th December 2020. In the five months leading up to her death she contacted her GP multiple times without her cancer being diagnosed. In her memory, Jess's family established **The Jessica Brady CEDAR Trust**, which is campaigning for Jess's Rule: "three strikes and rethink", a proposal that would encourage GPs to rethink a diagnosis when a patient returns three times with the same symptoms or concerns.

Government officials are engaged with the Brady family. As part of efforts to highlight the issues raised by Jess's care, NHSE are featuring her case in the 2024 NHSE Primary Care Patient Safety Strategy to raise awareness of the need to 'rethink' when symptoms remain persistent or unexplained after multiple presentations. The strategy is a clinically led approach for primary care professionals to improve patient safety in general practice.

I also noted your comment on the difficulties obtaining ECGs for children and young people in the community. NHSE is looking to improve paediatric expertise in the community by supporting local systems to implement neighbourhood multidisciplinary teams for children and young people. These will allow hospital paediatricians to work closely with primary care and improve access to this needed expertise in the community. Guidance was published to support systems in February 2025 and can be read at NHS England » Guidance on neighbourhood multidisciplinary teams for children and young people

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Yours sincerely,

Minister of State for Health and Secondary Care