Royal College of Paediatrics and Child Health
Leading the way in Children's Health

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[redacted]

Oliver Longstaff
Area Coroner
West Yorkshire (E)

Sent by email to: [redacted]

27 June 2024

Dear Mr Longstaff,

Re: RCPCH Response to the Inquest Touching the Death of Lily Grace Proctor
A Regulation 28 Report – Action to Prevent Future Deaths

Thank you for sharing your report with us regarding the tragic and untimely passing of Lily Grace Proctor. I have shared your report with other senior paediartic colleagues within RCPCH. The details have also been shared with the Association of Paediatric Emergency Medicine

We have read your report carefully and would like to offer a response to the matters of concern you have set out.

1. Screening tools to assist the detection of pulmonary thromboembolism / NICE Guidance NG158 "Venous thromboembolic diseases: diagnosis, management and thrombophilia testing"

We note your pertinent concerns that, in the absence of resources similar to those available when dealing with the adult population, clinicians working with children may be disadvantaged in diagnosing and treating the condition, to the obvious potential detriment of their patients. We would agree that this is the case.

We also note that the annual incidence of venous thromboembolism is very low in children, estimated at 0.07–0.49 per 10,000 children, making this a difficult diagnosis to make given the often insidious and non-specific early symptoms.

Paediatricians and other clinicians who see unwell children and young people could benefit from an effective tool to assist the clinical detection of pulmonary thromboembolism in children and young people. Also a national guideline on this topic that is specific to children could be helpful. We would look to the National Institute for Healthcare Excellence to take a lead on this work to help develop a further evidence base or consensus guidance in this complex area of clinical practice. If this is to be taken forward, the College would be happy to assist and provide clinical expertise.

2. Sharing information and learning for quality improvement across the paediatric community

RCPCH are currently reviewing our Emergency Care Standards and the information within your report has been shared with our Emergency Care Committee to inform this work.

The RCPCH Guideline Directory contains a full list of paediatric guidelines published by the National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN), as well as those from other Royal Colleges or paediatric specialty groups which meet the standards for RCPCH endorsement. If the above-mentioned paediatric guidance and screening tools are developed, they will be added to this directory to raise awareness across the paediatric community.

Our collegeis also responsible for supporting training and continuing professional development. We will ensure that the learnings from this tragic case are incorporated into any relevant courses, such as our course on How to Manage Non-Malignant Haematology.

The College will be sharing information and suggestions for local improvement from your report with our paediatric members via its patient safety portal. The anonymised information within your report, and anticipated response from NICE, will also be shared for discussion with the RCPCH Clinical Quality in Practice Committee, where further actions may be identified.

Thank you for seeking our views and reminding us of the importance of this work. Our sincere condolences are with Lily's family.

Yours sincerely

[redacted]

[redacted]
RCPCH President