

8 June 2023

Karen Henderson  
HM Coroner's Court  
Station Approach  
Woking  
Surrey  
GU22 7AP

Dear Dr Henderson,

I write in response to your regulation 28 report of 28 March 2023 regarding the very sad death of Louis James Rogers. I would like to express my sincerest condolences to his family.

We have considered the circumstances surrounding Louis' death and I have addressed below the matters of concern on which NICE can comment.

### **Earlier assessment and investigation of febrile seizures and national guidance for GPs**

In your report you explain that referrals for assessment and investigation of febrile seizures should be undertaken earlier to exclude a more severe underlying illness and that national guidance should be provided to ensure timely referrals to secondary medical services.

We believe that our guideline on [epilepsies: diagnosis and management](#) [CG137], which was in place at the time of Louis' death, is directly relevant to this case. The guideline covered diagnosing, treating and managing epilepsy and seizures in children, young people and adults in primary and secondary care and made recommendations on what should happen following a first seizure (section 1.4), diagnosis (section 1.5) and investigations (sections 1.6).

CG137 has since been replaced by our guideline on [epilepsies in children, young people and adults](#) [NG217], and includes updated recommendations on referral (see recommendation 1.1.1) and information and support after a first seizure (see recommendation 1.1.8 and 1.1.9).

There is also a [Clinical Knowledge Summary \(CKS\) on febrile seizure](#). While not formal NICE guidance, NICE commissions Clarity Informatics to develop CKS and make them available as a readily accessible summary of the current evidence base and best practice advice for primary care practitioners.

We therefore believe that there is sufficient national guidance in this area.

### **Sudden unexplained death in childhood associated with febrile seizures**

You also explain that evidence was heard suggesting that there should be greater emphasis on medical education, research and public information for sudden unexpected death in childhood (SUDIC) associated with febrile seizures.

NICE's chief medical officer, [REDACTED], and interim senior responsible officer for patient safety, [REDACTED], recently met with representatives of NHS England (NHSE) and the Royal College of Paediatrics and Child Health (RCPCH) to discuss this matter. We understand colleagues at NHSE have met with the National Child Mortality Database team and SUDIC charities and will be supporting a proposal for a round table to discuss and kickstart research and other actions in this area. The RCPCH has indicated that they are happy to support this approach and NICE would consider any request from NHSE to develop guidance in this area in the normal way.

We hope this reassures you that positive steps are being taken at a system level to prompt further research and action on SUDIC, and that this response addresses your concerns.

Yours sincerely,

[REDACTED]

[REDACTED]  
Chief executive