

Tom Osborne

Senior Coroner Milton Keynes
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Central Milton Keynes
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National Medical Director

NHS England
Wellington House
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30 October 2023

Dear Mr Osborne,

Re: Regulation 28 Report to Prevent Future Deaths – Rohan Godhania who died on 18th August 2020.

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 9th August 2023 concerning the death of Rohan Godhania on 18th August 2020. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Rohan's family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Rohan's care have been listened to and reflected upon.

I am grateful for the further time granted to respond to your Report, and I apologise for any anguish this delay may have caused to Rohan's family or friends. I realise that responses to Coroner Reports can form part of the important process of family and friends coming to terms with what has happened to their loved ones and appreciate this will have been an incredibly difficult time for them.

Age classification of 16 –18 year olds within the NHS

In your Report you raised the concern that there appeared to be a lack of clarity and consistent guidance across the NHS regarding the appropriate classification of teenagers aged 16 -18, and whether they should be treated as paediatric patients or as adults.

Most children's hospitals/departments are not commissioned to provide secondary and tertiary services for young people over the age of 16, with the exception of some rare cancers and those over this age are therefore often treated as adult patients. To improve young people's experience of care, outcomes and continuity of care, NHS England are committed to moving to a '0-25 year service model', offering person-centred and age-appropriate care for mental and physical health needs, rather than arbitrary transitions to adult services based on age and not need. We recognise that healthcare transition should be need and complexity based, not managed solely on diagnosis or what is routinely provided.

[NHS England's Children and Young People's Transformation Programme](#), working with key stakeholders, are developing guidance to aid the design of transition pathways that improve health outcomes for all young people. The support package will outline key principles of a 0 – 25 model of care and the core capabilities of staff

required for a consistent approach, while ensuring providers have the flexibility to decide what arrangements work best for them.

NHS England has been sighted on Chelsea and Westminster Hospital NHS Foundation Trust's review of Rohan's case. They have advised that it is standard operating procedure within the Trust that patients aged over 16 years are admitted to adult wards. The only exception is those with chronic health care issues who have not yet been fully admitted to adult care. The majority of patients within the Trust over 16 years of age are treated in the adult Emergency Department and are admitted to adult wards.

Guidance for testing for ammonia in Emergency Departments

You also raised the concern that there is a lack of guidance for testing ammonia levels in patients who present 'in extremis' with an unknown cause.

NHS England would not be the lead organisation for the relevant clinical guidance, and you may wish to refer your concerns to the Royal Colleges. NHS England has, however, engaged with the Royal College of Emergency Medicine (RCEM) on this case, and they have advised that they will be making an amendment to their existing [Acute Behavioural Disturbance guidelines](#) to specifically mention ammonia levels, should a clinician be considering the need for a metabolic screen.

The Royal College of Paediatrics and Child Health (RCPCH) [guidelines for the management of children and young people with an acute decrease in conscious level](#) also indicates plasma ammonia testing for young people with Rohan's clinical presentation.

NHS England's National Patient Safety Team have also undertaken work with the Royal College of Pathologists (RCPATH) on the specific issue of hyperammonaemia and ammonia testing. As a result of this a [Patient Safety Bulletin](#) was issued. This highlighted the need for 'prompt measurement of ammonia and action in the event of hyperammonaemia'.

The cause of Rohan's hyperammonaemia was Ornithine Transcarbamylase (OTC) deficiency, which is a very rare condition, and in Rohan's case, there was also late presentation. Urgent and Emergency Care (UEC) specialist colleagues at NHS England have also advised that there can be complexity in interpreting the results of ammonia levels testing. The Regulation 28 Working Group (please see penultimate paragraph for more details) will be discussing this case to consider any further actions and regional representatives will be sharing for awareness of this case with health systems across England.

NHS England has been sighted on the Trust's review of this case and notes that an action plan has been put together, to include ensuring pathways to urgent specialist face-to-face adult neurology assessment are clear and equal for all patients over the age of 16, and that the Trust's acute services should review their processes for early identification of treatable inherited metabolic disorders.

I would also like to provide further assurances on national NHS England work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors, and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around preventable deaths are shared across the NHS at both a national and regional level and helps us pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,



National Medical Director