Nadia Persaud
The Coroner's Court
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E17 8QP

[redacted]

National Medical Director
NHS England
Wellington House
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[redacted]

25 June 2024

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Andrew Ewin-Ripp who died on 4th November 2022.

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 2nd April 2024 concerning the death of Andrew Ewin-Ripp on 4th November 2022. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Andrew's family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Andrew's care have been listened to and reflected upon.

I am grateful for the further time granted to respond to respond to your Report, and I apologise for any anguish this delay may have caused to Andrew'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.

Your Report raised the concern that GP Practices are not required to carry out annual reviews of epilepsy patients. GP Practices required to follow and pay due regard to clinical guidelines. The National Institute for Health and Care Excellence (NICE) has issued clinical guidelines to general practice on annual reviews, including for Epilepsy.

The Royal College of General Practitioners (RCGP) has developed eLearning for GPs on Sudden Unexpected Death in Epilepsy (SUDEP) and seizure safety: *Summary of Sudden Unexpected Death in Epilepsy (SUDEP) and Seizure Safety | RCGP Learning*. There are also several additional tools and templates available for use in general practice to support structured reviews of patients with Epilepsy (for example, Ardens Healthcare Informatics have a variety of resources to support ongoing management: Epilepsy : Ardens EMIS Web).

Regarding your concern about medication compliance, patients on medication should have their medications reviewed at least on an annual basis. The General Medical Council's guidance for Good practice in prescribing and managing medicines and devices - professional standards - GMC (gmc-uk.org) states (Subsection 93): "Whether you prescribe with repeats or on a one-off basis, you must make sure that suitable arrangements are in place for monitoring, follow-up and review. You should

also take account of the patients' needs and any risks arising from the medicines." It is expected that any patient on repeat medication undergo a routine review.

Your Report also raises the concerns that there is no clear guidance for the long-term monitoring of patients with epilepsy and that there was no care pathway for incorporating urgent reviews in neurology clinics in response to patients reporting concerns. The National Institute for Health and Care Excellence (NICE) are responsible for the relevant guidelines: Epilepsies in children, young people and adults (nice.org.uk). Most patients with epilepsy will be discharged from follow-up once they are free of seizures for 12 months. At this point, their medication would only be changed if they had further seizures or other issues arose (such as possible adverse effects or consideration of pregnancy). Some patients with additional issues would be monitored for longer (see section 4.5.1 of the guidance). As per the above, patients should continue to have regular medication reviews with their GPs.

Providing advice on the longer-term management of epilepsy, including the need for regular medication and what to do if further seizures occur, is a central part of the management of epilepsy, provided by the neurologist and epilepsy specialist nurse. Access to both neurologists and epilepsy specialist nurses varies considerably across the country and few parts of the country have the capacity in the service for six monthly reviews of patients with active epilepsy. Many sites are now using 'patient-initiated follow-up' (PIFU) to allow patients to access the epilepsy nurse service promptly even when no longer under regular follow up to avoid the delays outlined in this report. The services in North East London are particularly pressed with fewer patients seen per head of population, and with fewer seen within 8 weeks (24% vs national average of 40%). Your Report has been shared with my regional London colleagues for their review.

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,

[redacted]

National Medical Director