

[REDACTED]
Honorary Secretary of Council

Ms Nadia Persaud
Area Coroner for the coroner area of East London

Sent by email to: [REDACTED]

24 May 2024

Dear Ms Persaud

Regulation 28 Report to Prevent Future Deaths - touching on the death of Andrew Ewin-Ripp

Thank you for sharing a copy of your report touching on the tragic death of Andrew Ewin-Ripp. I am responding on behalf of the Royal College of General Practitioners as Honorary Secretary to Council. Firstly, can I convey our sincere condolences to the family and friends of Andrew, I was deeply saddened to read of the circumstances around his death.

The Royal College of General Practitioners (RCGP) is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the 'voice' of GPs on issues concerned with education; training; research; and clinical standards. Founded in 1952, the RCGP has just over 54,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.

We have considered your report and offer our response focusing on the areas where the RCGP might have most significant influence to prevent further deaths.

We would like to outline our response to your four matters of concern in these three areas.

- 1) Education and support for Continuing Professional Development
- 2) Clinical Policy
- 3) General Policy and Health System Resources

1) Education and Continuing Professional Development

The RCGP has a role in developing the Curriculum for new GPs as well as providing ongoing continuing professional development (CPD) support for qualified members. The GP curriculum includes Neurology within its clinical topic guides <https://www.rcgp.org.uk/mrcgp-exams/gp-curriculum/clinical-topic-guides>. The College offers extensive support for CPD to members in different formats and we would like to highlight three relevant resources which are currently available to members:

▪ SUDEP

We currently have a resource available to members specifically on SUDEP and Seizure Safety (first produced in 2016 and updated in 2021). <https://sudep.org/article/sudep-action-rcgp-launch-sudep-e-learning>. It emphasises the role of General Practice in carrying out Epilepsy reviews using video and case studies in a 30min online resource. It highlights the use of the SUDEP and Seizure safety checklist <https://sudep.org/checklist> with resources for both professionals and patients. This course is free to access to all 54,000 RCGP members.

▪ Epilepsy Diagnosis and Management

We also have a series of regular Essential Knowledge Updates. In our Update 17 (April 2016 updated April 2024) there is a specific module on Epilepsy Diagnosis and management. A podcast freely available to all in which [REDACTED] talks about and promotes the e learning module highlighting the importance of regular annual review (EKU17: Epilepsy <https://podcasts.apple.com/gb/podcast/eku17-epilepsy/id1474942018?i=1000453462614>)

▪ Neurology Essentials

We published a Neurology One day Essentials update in February 2024, following a live conference which included a section on 'Transient loss of consciousness and Epilepsy'. Available for 6 months following registration.

2) Clinical Policy

The College supports the Clinical policy around Epilepsy management which is laid out in NICE Clinical Knowledge Summary (CKS) Epilepsy <https://cks.nice.org.uk/topics/epilepsy/>. This recommends undertaking an annual review of all people with epilepsy in primary care at least once a year. In the annual review the recommendation is to assess seizure control by asking about seizure frequency, severity and any changes since the last person was reviewed. There are clear guidelines around when to seek specialist advice for a person with confirmed epilepsy.

All suspected new patients should be seen by a Specialist and have the diagnosis confirmed and currently the discharge of the patient back to Primary Care is at the discretion of the Epilepsy Neurologist, however many patients are often given open access to the Epilepsy Nurse Specialists after discharge. The waiting times for 'Newly diagnosed Epilepsy patients' and 'Patients who may be uncontrolled' and need a Neurology review vary (in some areas this can be over a year. This may cause significant issues for patients who are waiting for a diagnosis or for further specialist input from a Neurologist. This issue is specifically highlighted in Andrew's case where the GP made repeated referrals for Specialist advice and appointments. We agree that there are no clear pathways or standards for urgent Neurology review like there are for 'Cancer care'. This often

places the Patient and the GP in an unacceptable position of managing the clinical risks without Specialist input and places further pressures on Emergency Services.

The NICE guidance includes written patient information and factsheets from 'Epilepsy action'. It would however be helpful to develop more specific decision support tools around epilepsy management such as the ones already produced for other disease areas by NHS England (<https://www.england.nhs.uk/personalisedcare/shared-decision-making/decision-support-tools/>)

The College is not responsible for Commissioning Services from General Practice. In England this role falls to NHS England. General Practice has however been funded for Epilepsy management through the GMS contract and Quality and Outcomes Framework (QOF) since 2004. There is a requirement to maintain a register of adults receiving drug treatment for Epilepsy (EP001). Between 2004 and 2014 there were 2 additional indicators which fell out of the annual review process i.e. those who were seizure free (EP002) and the number of women receiving information and counselling about reproductive issues (EP003). The EP002 and EP003 indicators were retired in 2014 by NHS England. There has just been a Government Consultation which closed on the 7th March around the future of incentives in General Practice including QOF so there may be changes in coming years. <https://www.gov.uk/government/consultations/role-of-incentive-schemes-in-general-practice/role-of-incentive-schemes-in-general-practice#how-to-respond>

3) General Policy and Health System Resources

Unfortunately, Andrew's case highlights the importance of supporting Patients with Epilepsy within a healthcare system. The resources within General Practice as well as secondary care are stretched and in General Practice the current priority is around recovering access to primary care (<https://www.england.nhs.uk/long-read/delivery-plan-for-recovering-access-to-primary-care-update-and-actions-for-2024-25/>). Waiting lists for outpatient appointments have grown and more than half the patients on Neurology outpatient lists are waiting over 18 weeks, in some areas a routine appointment is over one year. Developing a Personalised approach with the right integrated care pathways including timely access to support is challenging especially in areas where there are difficulties recruiting Epilepsy Neurologists and Nurses. In London there is one Epilepsy Neurologist to every 191 patients whereas in the North East of England it is one Neurologist to 755 patients. England has half the number of Neurologists compared to France and Germany and only two Epilepsy Nurses per 500,000 population (which is much lower than the NICE recommendation of 9 nurses per 500,000). There is an argument for providing more Integrated approach using a multiprofessional teams which include Specialised Pharmacists. The recent paper 'Integrated Care in Epilepsy Management: A Scoping Review of the Models and Components of Health and Social Care Delivery' examines some future areas for integration policy (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10921962/>).

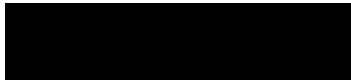
In some Integrated Care Systems there are local educational resources and liaison between Specialists and GPs and decisions around specific pathways. An example of this was a recent Epilepsy webinar held in the Frimley Integrated Health System outlining the risks of SUDEP at the end of the webinar (<https://www.youtube.com/watch?v=rLW3R671WjY>).

I would propose that the specific action RCGP could take would be to highlight NICE guidelines and current educational material on SUDEP through our Clinical Networks and member forums.

I would also recommend highlighting to NHS England the issues relating to waiting times for Epilepsy appointments and the need for standardised Urgent care pathways for patients with uncontrolled epilepsy.

I trust that this reply is helpful and if you have any questions, please do not hesitate to contact me. Our sincere condolences are with Andrew's family.

Yours sincerely

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RCGP Honorary Secretary