

7th September 2022

Poole Hospital
Longfleet Road
Poole
Dorset
BH15 2JB

██████████
HM Senior Coroner Mrs R Griffin
The Coroner's Office for the County of Dorset
Town Hall
Bournemouth
BH2 6DY

██████████
www.uhd.nhs.uk

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Dear Madam,

Re: Gaia Kima Pope-Sutherland

Thank you for your letter of 21st July 2022 enclosing the Regulation 28 Report to Prevent Future Deaths following the conclusion of the Gaia Pope-Sutherland inquest.

You may recall that ██████████, Head of Litigation and Inquests, attended all the Trust evidence and was present for many additional days of the evidence that you heard.

I welcome your letter seeking to ensure that future deaths are prevented and that any risks to patients around epilepsy care are minimised.

I understand that your concern arises from the evidence of Specialist Epilepsy Nurse ██████████ who indicated (point 1 (iii)) that there are 10,000 patients in Dorset with epilepsy who are overseen by two specialist epilepsy nurses, and felt that there were insufficient resources to treat the patients.

I have asked my Senior Management Team to analyse the epilepsy data, and they discussed the matter further with Dr ██████████ and Specialist Nurse ██████████ in order to understand the figures outlined to you during evidence. The data itself comes from the Dorset Epilepsy Dashboard. The Dashboard draws in information from GPs and relates to clinical coding, capturing information such as the types and groups of patients, including socio-economic background, pregnancy and patients suffering with learning disabilities. As at 19th August 2022 the Dashboard showed there were 10,749 patients with epilepsy in Dorset (9,916 adults). Of these patients it is estimated that 50-60% are seizure free, giving figures of 3,966 – 4,958 adults with active epilepsy. The Dashboard is a live programme and figures will change daily. The information it captures continues to be developed with the next iteration planned for Autumn 2022.

Nurse ██████████ has confirmed that in terms of these active patients, contact with them can be via telephone, emails or seeing them in the nurse led clinic. Frequency of contact from a patient however can be very variable, and is difficult to capture accurately in statistics. Nurse ██████████ has explained that for some patients, they may call just when they have a crisis, whereas others may call weekly or even more frequently, which means the nature of the demand for the service is unpredictable. Nurse ██████████ estimated that in terms of nurse led

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clinics, each nurse would see approximately 1,300 patients each year in clinic (i.e. a total of 2,600 for the service) in addition to telephone and email contacts. We hope this is helpful clarification.

Turning to your specific Preventing Future Death concerns:

2 (i) Lack of resourcing of epilepsy services

I am pleased to inform you that since the Gaia Pope-Sutherland inquest concluded the Trust has appointed a new full time Band 4 epilepsy co-ordinator to the team, who directly supports the two epilepsy specialist nurses. It is anticipated that the successful candidate will commence in post on 1st October 2022. The main duties of this role include:

1. To work without direct supervision with individual patients as delegated by the qualified Nurse to ensure that treatment plans have been implemented and to monitor the impact of medication changes including looking at seizure recording. To also help implement lifestyle changes which may impact on seizure control.
2. To work using a holistic approach to identify patient's goals for care and agree a personalised care and support plan.
3. Emailing – as appropriate - referrals to other teams and agencies e.g. Steps to wellbeing, social services, Community Learning Disability Team and Homestart.
4. Monitoring patient attendance at appointments and following up vulnerable patients who do not attend as appropriate. Work closely with the frequent attender team based in the emergency department and the ambulance service.
5. Following up patients who present to the emergency department with seizures and ensuring that a pathway is in place for future nurse or consultant appointments as appropriate and signposting to advice for patients waiting to be seen.
6. Reviewing and typing updated protocols, policies, patient information leaflets and other documents as required.
7. Setting up a webpage for the service and monitoring it's use and update as required.
8. Assisting in running patient wellbeing groups, and training as required under the direction of the Qualified Nurse.
9. Helping patients to access self-management education courses, peer support or other interventions that support them in managing their long term condition and improving their health and wellbeing.

The Band 4 epilepsy co-ordinator will report directly to the two epilepsy nurses and Dr [REDACTED]

In addition, the Trust is currently in the process of recruiting to the epilepsy team a part time 1 day a week Band 7 specialist nurse. This is a temporary post with funding for 12 months. The successful candidate has a long track record of dealing with Children & Young Persons who suffer from epilepsy which will be of great assistance to young people transitioning to adult epilepsy care. Whilst this individual is employed through our bank, we will be reviewing the impact, with the aim of developing a substantive model and funding, as part of the system working through the Integrated Care Board's review.

In relation to your request for consideration of a review of the nursing resources in epilepsy care locally in the Dorset Epilepsy Service, I can confirm that the Integrated Care Board (ICB) are carrying out an 8 week review which started on 11 August 2022. The review team, informed by the Getting It Right First Time (GIRFT) reports for neurology and epilepsy, are looking at the entire Epilepsy and Neurology service. This will be specifically considering:

- Local GIRFT review of Dorset Neurology Services in 2019
- National GIRFT Review of Neurology Services 2021
- Relevant NICE Guidance
- MHRA Drug Safety Updates
- Neurology Clinics
- Paediatric to Adult Services Transition
- Neurology and Mental Health
- Workforce resources

We have shared our GIRFT reviews of 2019 and 2021 and are currently working collaboratively with the ICB to assist the review. Those involved in the review include the UHD Chief Medical Officer, senior members of the Neurology team and our Productivity and Efficiency lead. We are awaiting the timescales to be confirmed for the ICB to share the findings of the review. However, it is envisaged that the review will be followed up by a longer term joint working group to take forward the recommendations.

2(ii) Communication between neurology and psychiatric teams

I am grateful for the clarification received on 26 July 2022 that the concern in relation to communication does not relate to the Trust at a local level and is directed at the position nationally and the national body for neurology services.

I plan to update you on progress in approximately 12 months to allow time for the recommendations of the ICB to be considered and actions identified. I hope this is acceptable and in the meantime if you have any further queries please do not hesitate to contact [REDACTED]

Yours faithfully

[REDACTED]

Chief Executive Officer

