

02 February 2024

Private and Confidential

Ms Sonia Hayes
HM Area Coroner for Essex Coroner's Office
Seax House
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Chelmsford
CM1 1QH

Chief Executive Office

The Lodge
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Wickford
Essex
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Dear Ms Hayes

Master William Brian Kin Gray (RIP)

I write to set out the Trust's formal response to the report made under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and regulations 28 and 29 of the Coroners (Investigations) Regulations 2013, dated 8th December 2023 in respect of the above, which was issued following the inquest into the death of William Gray (RIP) .

I would like to begin by extending my deepest condolences to William Gray's family. The Trust sympathises with their very sad loss of their young child.

The matters of concern as noted within the Regulation 28 Report have been carefully reviewed and noted. I will now respond in full to these concerns in the hope that this provides both yourself and William Gray's family with comprehensive assurance of changes that have been made at the Trust to address the concerns you have raised.

Concern a) The Asthma & Allergy Children's and Young Persons Service (the Service), at the time of William's initial referral to the Service in 2018 this consisted of one nurse for approximately 2000 children, and this increased to two nurses in November 2020. The evidence heard is that whilst the number of nurses has increased so has the geographical area that the Service covers, and that there are ongoing plans to increase this further. The Service remains under resourced whilst attempting to expand.

Response:

We agree that there were demand and capacity challenges in the service which the Trust has raised with local commissioning bodies over time to try to resolve. This matter was first raised in 2018 and continues to be discussed with the local Integrated Care Board.

The Trust has noted the valid concerns raised by the family as well as the Court in terms of resource, and has again reflected on service need and the required resources in order to meet demand.

In line with the evidence presented as part of this Inquest, the Trust had a 1.0 whole time equivalent (wte) Band 6 in post at the time of the incident to deliver a community specialist asthma and allergy service. The role had a large caseload, however the remit was narrower

than it is currently. The role provided telephone review assessments, face to face initial patient assessments in local clinics, attendance at multi- disciplinary meetings and Asthma and Anaphylaxis training and education to local school nurses and health visitors, as well as in preschool nursery settings.

In 2018 EPUT co-hosted a South East Essex Children Asthma and Allergy system-wide workshop where the benefits realised by the limited service was widely recognised.

The Commissioners agreed to support the development of a business case for additional investment. The service reviewed the national models of good practice and with the support of the Commissioner, prepared a business case for additional investment into the existing service. Unfortunately due to the Covid pandemic, this was delayed as the Commissioners were redeployed to alternative roles. Subsequently, an opportunity arose to apply to NHS England for pilot monies to expand the integration into primary care networks and to promote the 'Asthma Friendly Schools Initiative'. The business case prepared for the expansion of the existing team at the previously co-hosted workshop was submitted to NHS England requesting an additional 8.0 wte Band 6s to deliver an enhanced service in South East Essex. In 2021 the service was awarded an additional 3.0 wte Band 6s to deliver a pilot in local surgeries and to implement the Asthma Friendly Schools Initiative. Whilst the Trust was not awarded the full application of 8.0 wte, we were able to recruit to 3 further roles which has had a positive effect on service delivery.

The service continually endeavours to work hard to improve and deliver a responsive service to those who are referred to the Asthma and Allergy Service for support. Service provisions and compliance is monitored to ensure we continue to maintain a responsive service. Further, children are safety netted via signposting to GP's and charities such as Asthma + Lung UK and Allergy UK.

Since 2018 the service has seen an increase in the complexity of need in the local population and observed challenges for patients and parents accessing timely support from both primary and secondary care. In collaboration with the Commissioner and Secondary Care, the service has responded to system pressures by upskilling our nurses in non-medical prescribing, Tier 4 Asthma training and Association for Respiratory Technology & Physiology (ARTP) accredited Spirometry training. This has afforded the service users the option of opting to access the service more frequently as it is more accessible- for example for prescriptions, preventative inhalers, and spirometry assessments and for support to progress secondary care referrals.

In light of the service increasing its levels of expertise, it was viewed as a one stop shop for all types of requests from minor to urgent, however, the service now has clearer communication pathways for responsibility of care according to clinical need.

Whilst the total patient caseload has remained similar to previous years the number of patient contacts (face to face and non-face to face contacts) has increased substantially -by 75.5% in 2023 compared to 2018. The service strives to remain accessible but to maintain a safe and efficient level of service provision, a review of the existing support issued by the ICB has been commenced.

The above detail is set out in an effort to demonstrate to the Court, the acknowledgment that greater support is required in relation to demand, and the plans in place to address this.

It is of note that the geographical boundaries of the area remains the same but the population has grown and the referral volume has increased by 75%.

Due to the close working relationship between the Service and the ICB and the ideas generated for service development, NHS England has awarded monies to develop and implement the following:

- The Asthma Friendly Schools training to educational staff to ensure safety of children and young people within school.
- To upskill the GP practice nurses and enhance the GP's knowledge regarding evidenced based medicine management,
- Direct patient care will continue to be delivered and remain in South East Essex only.

The service developed an internal service development plan and a project group with the full engagement and support of the ICB Commissioner, who has also been advised of the content of this Regulation 28 Report.

The clinical lead nurses attend the bi-monthly Mid and South Essex Asthma and Allergy Network meetings (which includes attendance by the MSFT Specialist Consultant Clinical Lead and the Primary Care Networks Clinical Lead) to engage and collaboratively work together to deliver more joined up care and develop clarity and understanding of functions. The team participates in the East of England Asthma network comprising of a number of expert multidisciplinary professionals in the speciality of asthma who share best practice and ideas for further service development.

Prior to this Inquest, the service had already recognised improvements were required to effectively and safely improve the efficacy of clinical practice and continues to do so on a daily basis:

- Reviewing the service eligibility criteria
- Partnership working with the integrated care system to ensure the service remit is understood to be a supportive specialist service and not an urgent /emergency service. This remains the remit of primary and secondary care.
- Reviewing the SOP and Service Business Continuity Plan
- Reviewing the care pathway with partners
- Remodelling the community specialist asthma service offer – with engagement from system partners so there is greater clarity on roles and functions of all
- Review of the assessment templates and proforma documents to ensure equity and consistency of the assessments undertaken and the documentation recorded.
- Review care plans, symptom management plans, and letter templates
- Reviewing the eligibility of the respiratory caseload
- Review of the rag rating criteria of the Amber/Red/black critical caseloads to ensure the correct process of the next steps are identified i.e. once stable referral back to primary care (Amber). If remains uncontrolled, despite supportive management, onwards escalation and referral to secondary care (red) and tertiary care (black critical
- The Service holds clinical supervision once a month.
- The Service holds Difficult Asthma Meetings with the secondary care team every 3 months and a monthly Difficult Asthma Meeting within our team.
- Difficult Asthma Clinic held once a month at the hospital between the service and Secondary care team
- Continued good relationship with Secondary Care team who supports our service in caring for the patients
- Implemented the use of video conferencing (AccuRx) to visually perform remote assessment, although please note this does not afford the opportunity to perform chest auscultation which would indicate the presence of wheeze. This method of virtual assessment can demonstrate the teaching of peak flow and inhaler technique and enable

assessment.

- Timetable of clinics encompassing face to face assessments, AccuRx and telephone review assessments.
- Dedicated appointments times pre-booked in advance to ensure parent/carer/ patient response uptake
- We are working closely with our Commissioners at MSE ICB to continue to seek opportunities for additional resources whilst transforming the service within current staffing capacity.

Concern b) The Service continued to operate during the pandemic and did not introduce video calls when they could not make face-to-face attendances. There was no risk assessment of the impact on the Service, and no audit of whether this was sufficient to manage the Service. There is no contingency plan in place should this issue arise again

Response:

The Children's Asthma and Allergy Service have learnt many lessons from the practices undertaken during the pandemic and recognise video consultations could have benefitted patients at the time and may have helped improve the review assessments and important patient observations, and the service regrets that AccuRx (video consultation platform) was not deployed earlier.

Following a successful pilot of the AccuRx, the service has now implemented its use and blended this into the timetable of review assessments, offering service users an initial face to face clinic assessment, followed by a review assessment utilising AccuRx. With the option of an additional telephone review assessment. The app helps improve communication between the Service and service users. The patient image feature in AccuRx is designed to enable patients to attach images to provide clinicians with the additional information to inform their care. The Business Continuity Plan has been updated which now includes the use of video consultations and alongside new and additional aerosol generating safe venues for face to face assessments such as the bespoke Clinician at Rochford Hospital and specially identified clinic spaces in primary care settings risk assessed to be covid secure. The Standard Operating Procedure (SOP) and Business Continuity Plan now include clarity on when video consultations should be considered for use:

The service criteria for utilising AccuRx is the following;

- To be used as the preferred contact following the initial assessment.
- Any child/young person where there are concerns regarding inhaler or peak flow technique
- Any child/young person where there may be safeguarding concerns and face to face appointments are difficult to obtain.
- Any young person who are in their GCSE years or undertaking exams.
- A home where there is suspected damp/mould.

AccuRx does not replace the importance of seeing the patient in a face to face setting therefore if there are concerns regarding the patient, utilising face to face clinics/home visits will be a priority over AccuRx or telephone clinics.

Concern c) The Service relied on telephone contact, Nurses did not speak to William although he was old enough to be involved in his care

Response:

Current practice is to ensure all nurses request to speak with the child, if they are old enough, at all consultations - whether this is via telephone or video. During face to face clinic

appointments and home visit consultations, the Child / Young Person (CYP)'s view of their asthma is recorded within the voice of the child section of the electronic patient record to ensure all relevant parties including the GP and acute care clinicians are able to view this.

The service model provides pre-booked appointments determined by clinical triage and acuity of clinical presentation, which affords service users the opportunity and dedicated time to seek supportive management; however this provision is flexible according to patient clinical need. Record keeping is undertaken at each consultation to ensure contemporaneous and accurate documentation, to include potential referral and escalation to secondary care.

The outcome of all clinic consultations are documented within the patient record. Annual record keeping audits are undertaken monitor the consistency of assessments. This practice is further monitored during clinical supervisions sessions, caseload reviews and random spot checks.

Lessons learnt

In order to continue to learn lessons from this unfortunate tragic event, the service has undertaken a review of the existing capacity and demand, to identify the maximum effectiveness and efficiency of the current resource for the service user. Resulting in a refined service model with a robust patient journey either returning to primary care once stabilised or transition onwards to either secondary or tertiary care. As a way in which to manage risk, asthma care is shared amongst the multidisciplinary team, which includes primary care, secondary care and tertiary care.

Whilst being mindful of not repeating the evidence provided to your Court during this Inquest, we respectfully re-iterate the assurances set out in the learning statement submitted during the inquest and the subsequently developed Action Plan to monitor compliance for the service which highlighted the following:

- a) To ensure evidenced-based education and training for all MSE paediatric staff regarding medical devices involved in the management of Asthma. This was completed accordingly with the ward staff at Southend Hospital and then the subsequent employment of the acute clinical nurse specialist for asthma has continued with this for all acute paediatric staff.
- b) All CYP to receive a written Asthma Action management plan at each children's community Asthma & Allergy nurse consultation. The service has adopted and implemented the BEAT asthma/wheeze action plan.
- c) The Children's Community Asthma and Allergy (CAAS) referral form content has been reviewed and updated to provide safety netting and prioritisation or exclusion criteria. This has been completed and revised in accordance with the clinical lead for the integrated care system.
- d) CAAS assessment of CYP medication and inhaler technique – medication storage and environmental factors. This is assessed at every face-to-face visit and is discussed during video consultation/ telephone reviews.
- e) Upon discharge from the acute provider, an initial contact is actioned within five working days from hospital discharge, pending a face to face initial assessment scheduled within two weeks. Allocation of the Rag rating criteria to support patient directed contact
- f) All CYP presenting to the ED with a suspected diagnosis of asthma are reviewed by the CAAS. The service is offered to those who have attended the ED on one occasion.

- g) Complex patients with uncontrolled asthma are reviewed by the lead paediatrician and CAAS at the monthly joint clinic and excellent collaborative relationships established.
- h) The outcome of all clinic consultations are documented within the patient record. Annual recordkeeping audits are undertaken to demonstrate compliance with the recordkeeping template to ensure equity and consistency of the assessments.
- i) Since the pilot integration of the children's asthma and allergy service into the primary care networks, all GP practices have been requested to share access of the patient record, which means the nurses are able to view the prescription history prescribed for the patient by the GP./practice nurse.
- j) The service has developed a protocol which includes the required frequency of contacting patients, investigations required, symptom management and a robust guide on how to recognise and escalate patients who have high risk asthma. Patients/families are now specifically asked how many times they use their inhaler, i.e. it was previously more than 3 times a week – This has now been amended to more than 2 times a week. Additional questions such as symptoms affecting their sleep and ability to take part in activities/exercise are also enquired. If the patient has sufficient developmental understanding, the Asthma Control Test score is implemented
- k) Complex uncontrolled asthma patients who have progressed through the Amber caseload with minimal improvement are discussed at peer clinical supervision sessions and difficult asthma meetings as appropriate. Caseload reviews are undertaken with the team at three monthly intervals with the RAG rating allocated, in order to apply the relevant safety netting for the service user.
- l) All service providers to ascertain if parents/carers are able to read written care advice or directions provided. Documented within the patient record and a number of translated care plans are available to families
- m) Databases are compiled / reviewed of all service users who have been offered appointments and declined the service offer
- n) All CAAS staff to undertake the online smoking cessation course, completed for existing staff members and will be provided to new starters in the event of staff recruitment.
- o) All staff receive notification of updated nice guidance, this is circulated for information and the service is measured against the baseline assessment tool provided by NICE.
- p) All new starters on induction to the services receive the relevant SOPs/ policies
- q) To continue to develop links between universal services and the CAAS to improve education and training, to promote safe management, by addressing potential symptom management concerns/issues. Attendance at the universal services education forums is timetabled on a rolling programme and a database collated.

I hope that I have provided reassurances around the steps that we have taken to address the issues of concern contained within your report. We know there is an acute need to embed and effect change, hence we will monitor the above provisions to ensure these are contributing to our overall aim of keeping patients safe and delivering therapeutic care.

Please do let me know if you require any further information at this stage, including copies of any of the documents referred to above.

We will await your direction before sharing a copy of this reply with the family.

Yours sincerely

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Executive Chief Operating Officer / Deputy CEO