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Children & Family Health Devon

NHS
Devon Partnership
NHS Trust

CONFIDENTIAL

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Date: 3rd April 2025

Ms Louise Wiltshire
Assistant Coroner
County Hall
Topsham Road
Exeter
EX24QD

Sent via e-mail [redacted]

Dear Ms Wiltshire

Re. Mr William Antony Northcott – Regulation 28 report.

I write in my capacity as Chief Nursing Officer at Devon Partnership NHS Trust (the Trust) in response to your regulation 28 report dated 27 January 2025.

Can I first of all pass on my condolences to Mr Northcott's family and friend's.

In your report you highlighted areas of concern to The Pembroke Medical Practice, Devon ICB, Medicines & Healthcare Projects Regulation Authority along with us Devon Partnership NHS Trust (DPT). In respect to the concerns pertinent to DPT I respond as below:

(1) The inquest heard evidence that there should be regular repetition of information to patients suffering from treatment resistant schizophrenia about the risks and red flags associated with the side effects of taking Clozapine. Since William's death Devon Partnership NHS Trust has set up Clozapine clinics which provide the opportunity for staff who are familiar with the side effects associated with Clozapine to discuss these with patients attending for their monthly phlebotomy appointments (required for the purpose of monitoring their white blood cell count).

At these appointments healthcare professionals will specifically ask patients about their smoking habit, caffeine intake, bowel movements, hypersalivation, sedation, nausea, incontinence, heartburn, infection, and medication changes, in addition to open questions about any other side effects a patient might be experiencing. I am also assured that Devon Partnership NHS Trust will be including additional questions to be discussed at this appointment surrounding recent physical illnesses, palpitations, chest pain, breathlessness and dizziness.

[redacted]

MINDFUL EMPLOYER

Currently around 60% of the cohort of patients prescribed Clozapine who are under the care of Devon Partnership Trust have access to these clinics. The other 40% will attend their GP surgery for their monthly Clozapine phlebotomy service. The phlebotomy service provided at a GP practice is usually an appointment with a non-qualified member of staff, who will not have been specifically trained in the side effects of Clozapine. I am therefore concerned that the level of care provided to patients attending Clozapine clinics on a monthly basis, is likely to be superior from the care provided to those patients who attend their GP practice. In particular, I am concerned that any discussion and repetition of information surrounding regular flags and side effects associated with Clozapine, and advice about when to seek medical attention, will be significantly more limited for those patients attending their GP practice than for those attending the monthly Clozapine clinics. I am also concerned that this limitation is likely to extend further than the 40% of patients in receipt of Clozapine under the care of Devon Partnership NHS Trust and that this may be a national issue.

We recognised that there is variability in the quality and frequency of side effect screening and monitoring processes undertaking for patients prescribed Clozapine.

There are around 230 patient that attend the DPT lead specialised Clozapine clinics where Physical monitoring and side effects screening occurs in accordance to the regularity of when blood test is required. This varies between weekly, two weekly or every 4 weeks. However, the 40 % that accounts for 160 patients that attend GP surgeries where the side effect monitoring and screening does not occur. For this group we will be implementing the following

As a Trust we have developed a business case in order for the organisation to increase resources and to bring all the patients receiving Clozapine onto dedicated Specialist Clozapine clinics across Devon in Barnstaple, Exeter and Torquay (excluding Plymouth where Livewell provide mental health services) to receive the Gold Standard in Physical health monitoring and side effects screening.

(2) At post mortem examination William was found to have a significantly enlarged heart and left ventricular hypertrophy. This was not known to those caring for William in life. Clozapine is a cardiotoxic drug, and is often used in conjunction with other drugs which may also have a cardiotoxic effect.

The risk of myocarditis is reasonably well explained in Devon Partnership NHS Trust's policy documentation, but there is less of a focus on cardiomyopathies which would include left ventricular hypertrophy. I understand that the Trust's guidance is based on national guidance. Annual ECGs are required for patients prescribed Clozapine and questions about cardiac function will now be asked at monthly Clozapine clinics. However, I understand that ECGs are not a diagnostic tool used to assist in the diagnosis of cardiomyopathies such as left ventricular hypertrophy and that left ventricular hypertrophy can be asymptomatic. I also understand that an echocardiogram may be able to identify such cardiomyopathies, but that this is not currently required on initiation of Clozapine or routinely at any other time whilst a patient is taking Clozapine.

I am concerned that these cardiomyopathies could therefore go undetected in patients prescribed Clozapine and leave them at unknown increased risk of fatal cardiac arrhythmias, as occurred in William's case. Given that the Trust's guidance is based on national guidance I am concerned this may be a national issue.

Following your concerns we have reviewed the evidence based regarding Clozapine physical health monitoring and will be continuing seeking expert opinions as regarding the screening for cardiomyopathy in unsuspected patients to decrease the risk of harm.

Myocarditis has a number of clinically well-defined features that makes it slightly easier to be identified in earlier stages of prescribing. It is more likely to occur within the first 8 weeks of commencing Clozapine treatment, the frequency is in a 3% of patients. It is a highly suspected condition in patients that present with fever above 38 degrees, chest pain, a heart rate above 120 bpm and respiratory rate of 20/ min. At blood test a raised troponin and C - reactive protein (CRP) above 100 mg would support findings. The florid presentation is identifiable by trained health professionals triggering an alert to activate a sudden cessation of Clozapine and seeking medical review and treatment

However the screening for **cardiomyopathy** for unsuspected patients is significantly difficult. The current evidence based does not support the use of echocardiography as a pre-monitoring requisite given the excessive cost that this will bring. The incidence of cardiomyopathy in people taking Clozapine has been cited as 0.02% of patients in the USA and 0.1% in Australia. This is 1 in 1000 to 1 5000 patients taking Clozapine.

In the Australian study where the designed a protocol that included Echocardiography it was found that Echocardiography are not viable as a screening tool for cardiomyopathy [Murch S, Tran N, Liew D, Petrakis M, Prior D, Castle D. Echocardiographic monitoring for Clozapine cardiac toxicity: Lessons from real-world experience. Australasia Psychiatry 2013;21(3):258–61. Search PubMed].

The prevalence of cardiac dysfunction in patients commencing Clozapine is high. Routine echocardiography is not useful in the detection of Clozapine-associated myocarditis. Although cardiomyopathy may be identified, it is rare and associated with significant treatment costs. Recommendations for routine echocardiographic monitoring should be re-examined

It is recommended for the clinician to be alert of any sign or symptoms of congestive heart failure so that the appropriate referral for expert opinion is sought. The key symptoms are; new complaint of tiredness without obvious medication changes, leg swelling or ankle oedema, palpitation and or shortness of breath.

Further Developments: We are in communication with the Royal College of Psychiatrists (RCPsych) seeking information regarding **The William's Protocol**. We understand in a blog posted at the RCPsych that the William Protocol is a suite of measures worked between [redacted] (sister of William) and the Royal College of Psychiatrists. It is stated in the article that these measures will ensure far stricter monitoring of Clozapine, education for clinicians, families and carers on red flag side effects, better physical care and alongside address the unfair prejudice faced by people with severe mental illness.

In order to get a deeper understanding on what is proposed by the William Protocol we as an organisation will be meeting with [redacted] the Royal College of Psychiatrists Presidential lead for Physical Health to gather further details.

At present the national guidelines available to us do not recommend the routine use of echocardiography as a screening tool in patients to be treated or receiving Clozapine treatment.

(3) It is clear that patients suffering with treatment resistant schizophrenia are complex, and as such there are often a number of different agencies involved in an individual's care. In addition, there are often multiple members of the same team involved in an individual's care. During the inquest it became clear that, at times, communication of important issues was not as clear as it should have been. I note that Devon Partnership NHS Trust has significant training available for its staff and other agencies it engages with in relation to patients who are prescribed Clozapine. However, it would be of great assistance to understand what Devon Partnership NHS Trust is doing to ensure that optimum communication of key information is achieved within the community mental health team, and when dealing with its other agencies involved in a patient's care.

Delivering mental health care for individual suffering Severe Mental Illness requires a multidisciplinary and multiagency approach, ensuring effective information sharing can be challenging at times.

There are a number of steps that Devon Partnership NHS Trust has adopted to ensure effective information sharing between those involved in the care of the patients.

DPT has adopted a new Electronic Patient Records (EPR) named SystmOne. This EPR is used by a significant number of others GPs surgeries (60%) in the county and when patients consent to information sharing it allows both primary and secondary mental health services to see the information entered. Meaning that the GP will have immediate access to the entry made by a Consultant Psychiatrist following a consultation and vice-versa. This is of tremendous importance as one can access physical health related and medication information. This of course requires the patient to consent information sharing and as already stated it is not used by all the GP practices. Of course EPR sharing does not constitute a communication device

Secondary Mental Health services communicate with primary care by sending clinic letters or e-mails. This tends to occur following consultations, assessments, reviews or any other clinically relevant interaction with patients.

As we developed and designed Systmone to meet the specific needs of the service we identified a number areas for improvements that can communication effective. Including

- A single individualised Care Plan across all DPT services which supports ensuring that the plan provides all the information pertaining to the patient promptly and in one place.
- Care Plans to be coproduced by patients together with the clinician and shared with family members and carers
- Other agencies such as the voluntary service will be having access to Systmone and consequently have access to the information relevant to patients taking Clozapine and their care plans
- Information regarding physical health and findings that requires action will require active communication escalation between clinicians with clear actions.

.I trust the above responds clearly to your questions,

Yours Sincerely

PP [redacted], Deputy Director Nursing

[redacted]

Chief Nursing Officer