REGULATION 28: REPORT TO PREVENT FUTURE DEATHS

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. [redacted], Chief Executive of NHS England, Skipton House, 80 London Road, London, SE1 6LH**
1	**CORONER** I am Xavier Mooyaart, an assistant coroner for the coroner area of Inner South London.
2	**CORONER'S LEGAL POWERS** I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.
3	**INVESTIGATION and INQUEST** On 1 July 2021 an investigation into the death of Charlie Marriage commenced. The investigation concluded with an inquest hearing starting on 9 December 2024 and a conclusion hearing on 21 January 2025. The conclusion of the inquest was that Mr Marriage died from SUDEP (Sudden Unexpected Death in Epilepsy), but this in the context of, and likely contributed to, by his lack of medication, despite his efforts to obtain it over the course of two days.
4	**CIRCUMSTANCES OF THE DEATH** Mr Marriage had a longstanding diagnosis of idiopathic generalised epilepsy and suffered grand mal seizures with no warning. The risk of these had become well managed with medication, in particular Fycompa (Perampanel). On Thursday 24 June 2021 he would finish his medication, but he expected to pick up a repeat prescription from a pharmacy in Uxbridge (he studied at Brunel University) the following day. He was then notified to self-isolate for Covid, which prevented the long journey to pick up his repeat medication. The following day he sought to obtain a new repeat prescription via his GP practice for a local pharmacy, but this was not recognised to be urgent in time. Both the GP practice and the university pharmacy were closed over the weekend. On Saturday 26 June he called 111, which promptly arranged for a "referral" for his medication to be sent to a local pharmacy. There it was not promptly identified that the Fycompa could not be supplied, resulting in several wasted calls to 111, and the loss of time and motivation. He was referred back to 111 by the pharmacist, though it was they that should have sought to find a solution. 111 identified that a clinician would be required to help resolve the situation, but Mr Marriage did not receive a call back from one. That

	night he suffered a seizure that caused his death at home. The lack of Fycompa likely increased the prospect of a severe seizure and contributed to his death. The growing risk of him suffering SUDEP over the 48 hours since his last dose had not been recognised or resulted in appropriate prioritisation, safety-netting, or an emergency supply.
5	**CORONER'S CONCERNS** During the course of the inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths could occur unless action is taken. In the circumstances it is my statutory duty to report to you. The **MATTERS OF CONCERN** are as follows. – (1) There are cohorts of patients who are medication dependant. For some their underlying condition is such that absent this medication they are at significant risk of a sudden crisis, and potentially death e.g. SUDEP, or Diabetic Ketoacidosis etc. These were described at the inquest as "cliff-edge conditions". (2) It is not apparent that these patients are currently identified within the health system as being at risk of a sudden crisis and death (absent their medication) so as to manage the following concerns giving rise to a risk of future deaths: (a) that such patients may not be fully aware of the risks of death associated with not being medicated and therefore may (i) not fully understand the importance of avoiding the risk that this scenario arises, and (ii) not have planned the likely best course of action in the event that it does (e.g. to go to A&E, or to approach an identified pharmacy for an emergency supply); (b) that the potential urgency and level of danger is not quickly identified and understood in the scenario where they seek medical advice and/or medication (i.e. that their potential vulnerability is not well recognised and communicated on/within the medical records accessed by those in the health sector, such that patients are not supported with appropriate urgency or safety-netting advice); (c) that it is not recognised that sending to them to a pharmacy may not reliably mitigate their risks quickly where it is unlikely the medication can be expected to be in stock (i.e. the risk that it may not be identified that for some patients their medication is not likely easily available on an ad hoc local basis); and (d) that they are given generic safety-netting/worsening advice, whereas such patients may not present with any developing or new before suffering a sudden crisis and therefore remain at significant risk without medical oversight until appropriately medicated.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe NHS-England has the power to take such action.

7	**YOUR RESPONSE** You are under a duty to respond to this report within 56 days of the date of this report, namely by Tuesday 25th March 2025. I, the coroner, may extend the period. Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise, you must explain why no action is proposed.
8	**COPIES and PUBLICATION** I have sent a copy of my report to the Chief Coroner and to the following other Interested Persons: the family of Mr Marriage, the Waterloo Health Centre, a then receptionist for the GP practice, SuperDrug, the locum pharmacist employed in a particular SuperDrug branch at the time, the London Ambulance Service, and Derbyshire Health United. I am also under a duty to send a copy of your response to the Chief Coroner and all interested persons who in my opinion should receive it. I may also send a copy of your response to any other person who I believe may find it useful or of interest. The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it useful or of interest. You may make representations to me, the coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner.
9	 **24 January 2025**