M. E. Voisin
His Majesty's Senior Coroner
Area of Avon

7 July 2025 REF: [redacted]

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** • **Secretary of State for Health & Social Care**
1	**CORONER** I am Debbie Rookes, Assistant Coroner for the Coroner Area of Avon
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 27 August 2024, an investigation was commenced into the death of Sarah Jayne Lewis. The investigation concluded at the end of the inquest today, on 7 July 2025. The conclusion of the inquest was: **Suicide** The cause of death was recorded as: 1a Acute toxicity of [redacted]

4	**CIRCUMSTANCES OF THE DEATH** In 2014, Sarah Lewis was diagnosed with Myalgic encephalomyelitis (ME)/ Chronic Fatigue Syndrome (CFS). Ms Lewis' ME was severe and as a result of her condition, she experienced severe and debilitating symptoms. This had a huge effect on her quality of life, and left her for the most part bedbound. It also impacted on her ability to seek professional support or be supported due to sensory sensitivity and aversion to visiting, or being visited. Ms Lewis had a history of anxiety and depression but this complex multisystem condition resulted in a deterioration of her mental health and left her wishing that she was no longer alive. On 8 August 2024, it was Severe ME Awareness Day. Ms Lewis was found deceased at home on 9 August 2024 but as she had not been seen for 2 days, it is likely she died the day before, on a day which was significant for her. Her death was caused by her taking an overdose of [redacted] with the intention of ending her own life. By ending her own life, she also ended the profound physical and mental suffering that she had endured. I heard that due to the severe nature of her illness, nothing could really be done to help her. She was therefore left knowing that there is no real treatment for ME, and there is no cure. Whilst there is an ME/CFS service provided by North Bristol , there are areas of the country where there is no provision.

5	**<u>CORONER'S CONCERNS</u>** During the course of the inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths will 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) Despite ME having received some more recent attention, the provision of ME services around the country remains inconsistent. I understand that there are still areas where there is no provision. The evidence revealed that a very important first stage for ME sufferers is that they receive a diagnosis and validation for their severe symptoms. Without provision of a service, there remains a risk that this will not occur. I was told that there is still a belief by some that ME is not real and this has a profoundly negative effect on sufferers and their ability to seek support. (2) Historically, there has been little research into ME. As a result of this, nobody knows what causes it, and there is therefore no cure. Whilst I note there has been a small investment recently in research, I was told that this is not enough, and that a perception remains about ME not being real. The resultant effect is that some ME sufferers have no hope that their symptoms will ever improve. (3) Other professionals do not understand ME, what it is or the symptoms it causes. This can be a barrier to those with ME receiving support, or accessing care/treatment they need. A hospital passport is now being utilised at North Bristol, which assists sufferers. However, it is not clear that this is being used in all areas, and there remains a lack of understanding about ME. Education and training about this has not been prioritised. (4) NICE issued update guidance relatively recently but it is not clear whether this has been fully considered or implemented by commissioning bodies around the country.

6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe you, the Secretary of State for Health and Social Care 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 2 September 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 [redacted], father of the Deceased, and to North Bristol NHS Trust, whose witness gave evidence at the inquest. A copy is also being sent to the Chief Coroner, and to NICE, as I understand that they relatively recently issued guidance. I am also under a duty to send the chief coroner a copy of your response. 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	7 July 2025 Debbie Rookes Assistant Coroner