

8 August 2025

Ms Debbie Rookes
Assistant Coroner
Coroner's Court
Old Weston Road
Flax Bourton
BS48 1UL

[REDACTED]

[REDACTED]

Dear Ms Rookes,

Re: Regulation 28 Prevention of Future Deaths Report in respect of Sarah Jayne Lewis

I write in response to your regulation 28 report, dated 7 July 2025, regarding the very sad death of Sarah Jayne Lewis. I would like to express my sincere condolences to Ms Lewis's family.

We have reflected on the circumstances surrounding Ms Lewis's death and senior clinical advisers within our patient safety team have reviewed the concerns raised in your report.

Following discussions with colleagues at the Department of Health and Social Care (DHSC), we understand they will respond fully to points 1 to 4. We make the following observations.

- 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.**

The provision and implementation of ME/CFS services is a matter for NHS England (NHSE) and Integrated Care Boards (ICBs).

In the cross-government [final delivery plan for ME/CFS](#) published on 22 July 2025, it was noted that NHS England has completed a stocktake of existing ME/CFS services. Following this, NHSE will publish a template service specification for mild and moderate ME/CFS which will be disseminated to all ICBs to inform their commissioning decisions and support quality of local service provision to match local needs.

The delivery plan also states that the DHSC, with NHS England, will explore whether a specialised service should be prescribed by the Secretary of State for very severe ME/CFS.

Our guideline on [myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#) [NG206] makes recommendations on the assessment and skills required for such a specialist service and NICE staff supported the development of the delivery plan.

- 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.**

When developing our guideline on ME/CFS [NG206] the independent guideline committee reviewed the relevant literature.

They made a number of [recommendations for research](#). As we develop guidance, we identify gaps and uncertainties in the evidence base which could benefit from further research. The most important unanswered questions are developed into research recommendations.

The commissioning and funding of such research is not within NICE's remit. [Funding is available from the National Institute for Health and Care Research \(NIHR\)](#) for projects addressing NICE research recommendations. We encourage researchers to apply for funding to generate new evidence to inform future NICE guidance.

- 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.**

Education and training is the remit of the professional colleges and the NHS. NICE has supported the development of [e-learning materials](#) consistent with NICE guidance on ME/CFS which we make available on our website as they are published.

NICE has also commissioned a Clinical Knowledge Summary (CKS) topic on [ME/CFS](#), developed by Clarity Informatics Ltd, which was published in May 2025. CKS topics are a source of advice and information primarily for health professionals working in primary care, but they do not constitute formal NICE guidance.

- 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.**

As mentioned above, service commissioning and delivery is the responsibility of the relevant NHS body.

I hope this response is helpful. Please do let me know if you require any further information and again, I offer my sincerest condolences to Ms Lewis's family.

Yours sincerely,



Chief Executive