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[redacted]

National Medical Director
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27 November 2024

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Maeve Bernadette Boothby O'Neill who died on 3 October 2021

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 7 October 2024 (amended on 8 October 2024) concerning the death of Maeve Bernadette Boothby O'Neill on 3 October 2021. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Maeve's family and loved ones. NHS England are keen to assure the family and the Coroner that the concerns raised about Maeve's care have been listened to and reflected upon.

Your Report raises concerns over the care provision in England for patients with severe Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS) and that there is currently no available funding for research and development of treatment for the condition.

NHS England has engaged with the Department of Health and Social Care (DHSC), who we note your Report was also addressed to, on these matters. Following a period of consultation with key stakeholders, including those with lived experience, and the publication of the interim delivery plan on ME/CFS in late 2023 under the last Government, the DHSC have confirmed to NHS England that the development of a final ME/CFS Delivery Plan to improve the experiences and outcomes for people with the condition remains a priority and that it is their intention to publish a response summary before the end of the year.

The summary will be shaped by the consultation responses, along with continued close engagement with stakeholders, and, with relevance to the concerns raised in your Report, will encompass the three broad themes of:

1. Attitudes and education
2. Research
3. Living with ME.

It is intended that the final delivery plan will be published by the end of March 2025. NHS England will support the DHSC on the implementation of the delivery plan and

we would refer the Coroner to the DHSC for further information on this, as well as details of existing investment and funding for research into ME/CFS.

In addition, NHS England has also established a specific working group to determine if additional support can be provided to commissioners of ME/CFS services. A stock take of existing CFS/ME services in England is being undertaken as an initial step. If it is of assistance, we can provide further updates as this work progresses.

Your Report also raises the concern that there is limited training for doctors on ME/CFS and how to treat it, particularly for cases of severe ME. There is currently a limited evidence base for the treatment of severe ME/CFS, which does create challenge to developing educational resource. However, in May this year, in development with DHSC, NHS England published the first of three new e-learning modules. An 'Introduction to ME/CFS' provides an overview of the potential causes, diagnostic criteria and management strategies. A further two modules, aimed at the NHS clinical workforces, are now in development, the first of which will cover management in primary care, followed by the third module which will provide guidance on the management of severe ME/CFS in secondary care settings.

It is appropriate that the National Institute for Health and Care Excellence (NICE) responds to the Coroner on your fourth concern regarding NICE guidance on ME/CFS and nutrition support for adults. NHS England has engaged with NICE on the concerns raised in your Report and will carefully consider the response from NICE in due course.

My regional colleagues in the South West have also considered your Report and have engaged with Royal Devon University Healthcare NHS Foundation Trust (RDUH) on your Report and the care delivered to Maeve. We understand that RDUH are in the process of developing formal pathways for acute admission and emergency admission for patients with ME/CFS and that the details of these will be shared with the Coroner by the Trust.

I would also like to provide further assurances on the national NHS England work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors, and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around events, such as the sad death of Maeve, are shared across the NHS at both a national and regional level and helps us to pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,

National Medical Director