ANNEX A

REGULATION 28: REPORT TO PREVENT FUTURE DEATHS (1)

*NOTE: This form is to be used **after** an inquest.*

	REGULATION 28 REPORT TO PREVENT FUTURE **DEATHS THIS REPORT IS BEING SENT TO:** 1. **Andrew Gwynne / Wes Streeting Department of Health and Social care** 2. **NHS England** 3. **NICE** 4. **Medical Research Council** 5. **National Institute for Health care and Research** 6. **Medical Schools Council**
1	**CORONER** I am Deborah Archer, Assistant coroner, for the Coroner area of The County of Devon ,Plymouth and Torbay.
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 26th October 2021 Senior Coroner Philip Spinney commenced an investigation into the death of Maeve Bernadette Boothby O' Neill who was 27 years of age at the time she died on 3rd October 2021. The investigation concluded at the end of a 2 week inquest I conducted on 9th August 2024. I further heard evidence from the hospital trust on the need for a Regulation 28 report on 27th September 2024. The findings I made discussed the fact that despite Maeve having been tube fed on one occasion during admission this was not sufficient for her to recover. The inquest heard that provision of care for patients with severe ME such as that which Maeve suffered from was and is nonexistent and that being placed on a ward that did not have expertise in her condition made her admission to hospital very difficult for her to endure. The conclusion of the inquest was Natural Causes and Box 3 recorded that she died at home after 3 admissions were unable to treat the consequences of her severe ME. Maeve Boothby O'Neill was suffering from severe ME during the period the inquest focused on, namely January – October 2021. This meant that she was bed bound and reliant primarily on her mother to provide personal care. She was admitted to hospital on 3 occasions during this period namely on 18th March,19th May – 3rd June and finally on 25th June -17th August. Despite attempts to treat her these ultimately failed and she died on 3rd October 2021.

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) During the course of the evidence it became clear that there were no specialist hospitals or hospices, beds, wards or other health care provision in England for patients with severe Myalgic encephalomyelitis (ME). This meant that the Royal Devon and Exeter Hospital had no commissioned service to treat Maeve and patients like her. (2) During the course of the inquest it became clear that there was no current available funding for the research and development of treatment and further learning for understanding the causes of ME / Chronic Fatigue Syndrome (CFS) . (3) During the course of the inquest it became clear that there was extremely limited training for Doctors on ME/ CFS and how to treat it – especially in relation to severe ME. (4) During the course of the inquest it became clear that the 2021 NICE guideline on ME did not provide any detailed guidance at all on how severe ME should be managed at home or in the community and in particular whether or not there is any necessary adaptation needed to the 2017 guidance on Nutrition support for adults : oral nutrition support, enteral tube feeding and parenteral nutrition.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe you have 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 3rd December 2024. 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 Interested Persons – Mr. Sean O'Neill, Ms Sarah Boothby, Barnfield Surgery, Devon County Council, Royal Devon and Exeter NHS Trust. I have also sent it to the ME Association, Dr Michael March, NHS Southwest England and Steve Moore, Chief Executive of the Integrated Health Board, who may find it useful or of interest. 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.
9	**7th October 2024** **Deborah Archer.**