



8th May, 2024

Deputy Neasa Hourigan, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 18001/24

To ask the Minister for Health if he will provide an update on the work of the myalgic encephalomyelitis working group established by the HSE; and if he will make a statement on the matter

Dear Deputy Hourigan,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the HSE's National Clinical Director for Integrated Care and National Clinical Advisor and Group Lead for Children and Young People (NCAGL C&YP) on your question and have been informed that the following outlines the position.

A Clinical Practice Guideline Group for Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) was initiated under the HSE's Office of the Chief Clinical Officer in 2022. The purpose of the Guideline Group is to facilitate the development of a clinical practice guideline to guide General Practitioners, Paediatricians and Adult Medical Consultants towards best practice in diagnosing and treating patients with these conditions.

Chaired by the National Clinical Advisor for Children and Young People, the Clinical Practice Guideline Group includes patient partners in addition to clinicians. The completed guideline would help inform health planning for patients with ME and CFS.

In order to develop this clinical practice guideline, it is important that there is adherence in the application and use of the HSE's National Framework for developing Policies, Procedures, Protocols and Guideline (PPPGs) 2016 and its development cycle stages (available at: [hse-national-framework-for-developing-pppgs-2016.pdf](#)).

The HSE's National Clinical Director for Integrated Care has commissioned a scoping exercise to ensure adherence to this HSE National Framework for developing PPPGs (2016) and to secure an agreed approach in developing the guideline, considering options available as part of this process.

It is envisaged that this proposed approach will be discussed with the Clinical Practice Guideline Group for Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS).

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely

Anne Horgan
General Manager

