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12th December 2019

Deputy Denis Naughten, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 49589/19

To ask the Minister for Health his plans to establish a registry of persons suffering from fibromyalgia in order that it is possible to ascertain the number of persons suffering from the condition; his view on whether it would be prudent to establish the registry alongside that of arthritis in view of the fact that more persons retire early as a result of fibromyalgia than arthritis; and if he will make a statement on the matter

Dear Deputy Naughten,

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 National Clinical Programme for Rheumatology on your question and have been informed that the following outlines the position.

The National Clinical Programme for Rheumatology (NCPR) is an advocate for the use of registries to improve patient care. The NCPR has proposed an Arthritis Registry in their model of care for rheumatology in Ireland. This will support the future development of services for patients with bone and joint diseases in Ireland and which would ultimately include Fibromyalgia.

Arthritis and other rheumatic and musculoskeletal disease (RMDs) affect almost one in four people in Ireland; the scale of implementation of a national arthritis is dependent on the health service having a unified electronic patient record in place. If funded, we propose to perform individual patient cohort studies of:

- rheumatoid arthritis,
- psoriatic arthritis,
- ankylosing spondylitis,
- connective tissue disease,
- vasculitis
- fibromyalgia

This will provide an evidence base for the development of an integrated care plan for RMDs in line with Slaintecare.



The NCPR is not aware of any evidence showing fibromyalgia causes more early retirements than arthritis, a cohort study of both patient groups would provide more information on the impact of these conditions.

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

A handwritten signature in black ink, appearing to read 'Tim Carey', with a horizontal line underneath.

Tim Carey
Assistant National Director

