



11<sup>th</sup> July 2024

Deputy Alan Kelly, TD  
Dáil Éireann  
Leinster House  
Kildare Street  
Dublin 2

**PQ: 27670/24**

**To ask the Minister for Health the total cost of establishing and maintaining a clinical care programme for ILD patients assuming approximately 5,000 active cases and 1,000 new diagnoses per year.**

**PQ: 27671/24**

**To ask the Minister for Health the estimated total ongoing costs of managing a patient registry for ILD patients across the public health system (assuming approximately 5,000 active cases and 1,000 new diagnoses per year).**

**PQ: 27710/24,**

**To ask the Minister for Health the estimated total cost of establishing and maintaining a clinical care programme for interstitial lung disease patients, assuming approximately 5,000 active cases and 1,000 new diagnoses per year.**

**PQ: 27711/24**

**To ask the Minister for Health the estimated total ongoing costs of managing a patient registry for interstitial lung disease patients across the public health system, assuming approximately 5,000 active cases and 1,000 new diagnoses per year.**

Dear Deputy Kelly,

The Health Service Executive (HSE) has been requested to reply directly to you in relation to the above parliamentary question(s), which you submitted to the Minister for Health for response. I have consulted with the National Clinical Director for Integrated Care (NCD IC) on your questions and have been informed that the following outlines the position.

Interstitial lung disease (ILD) includes diseases such as Idiopathic Pulmonary Fibrosis (IPF), characterised by progressively worsening respiratory function and high mortality.

In Ireland the disease is responsible for a significant clinical burden and is the third largest admitting respiratory diagnosis to acute hospitals with prolonged admissions and high mortality. Lung transplant remains the only effective cure. There have been significant improvements in new treatments for patients with ILD including new anti-fibrotic medications which can decrease progression of disease, but these medications can have significant side effects and are expensive to provide.

The HSE's National Clinical Director for Integrated Care has requested a scoping exercise be undertaken to review the evidence and assess the needs of the population living with pulmonary fibrosis/interstitial lung disease (ILD) and to determine how and where best their care provision needs are met.

Once the needs of this population are determined, the next step in the process will be to identify the resources required to design and develop a work programme, to address and meet these needs, and to identify the requirements needed to implement a suitable care pathway for this patient cohort.

This will be determined in tandem with making the best use of existing and planned resources in the acute and community settings to support this cohort of service users.



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



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**Anne Horgan**  
**General Manager**

