



Rannán na nOspidéal Ghéarmhíochaine  
Aonad 4A, Áras Dargan  
An Ceantar Theas  
An Bóthar Míleata  
Cill Mhaighneann  
Baile Átha Cliath 8

Acute Operations  
Unit 4A, The Dargan Building  
Heuston South Quarter  
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Dublin 8

30<sup>th</sup> January 2024

Deputy Cathal Crowe  
Dáil Éireann,  
Leinster House  
Kildare Street  
Dublin 2

**PQ 2495/24 To ask the Minister for Health if he will outline the timeline for the implementation of the European Reference Networks standards for ensuring data from all health settings is captured with regard to rare disease, i.e., community healthcare up to hospital settings.**

Dear Deputy Crowe,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted for response. I have examined the matter and the following outlines the position.

There are currently 24 European Reference Networks (ERNs), gathering over 1,400 centres of expertise from 26 countries in the EU. Since January 2022, Ireland has become a member to 18 ERNs, a significant achievement for the health service and in particular people in Ireland affected by rare conditions. This is a collaboration of over 40 Irish centres of expertise, led mainly across five acute hospitals.

To integrate the ERN model and system into the Irish health system is an ambitious and complex process. It will require a significant level of support and co-ordination at national and local levels as well as appropriate incremental funding to support ERN implementation and operationalisation. Funding is required to support ERN sites and Clinical Leads in the key areas of data management and care co-ordination. A HSE business case for ERN Integration has been submitted to the Department of Health. Timelines for implementation of the ERNs are dependent on when funding is received.

The Department of Health, through the office of the Chief Medical Officer, is currently leading out on the development of a new Rare Disease Plan for Ireland in collaboration with key stakeholders. It is expected that the new plan will be launched in autumn 2024. Areas of focus will include ERN integration and data management for rare diseases and the Department of Health will continue to work with the HSE with regard to funding and resources to support ERN integration.

I trust this information is of assistance to you but should you have any further queries please contact me.

Yours sincerely,

A handwritten signature in black ink that reads "Catherine Clarke".

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Catherine Clarke  
Assistant National Director, Acute Operations