



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
Military Road
Kilmainham
Dublin 8

14th March 2024

Deputy Pádraig O'Sullivan
Dáil Éireann,
Leinster House
Kildare Street
Dublin 2

PQ 9452/24 To ask the Minister for Health if he will supply data detailing the staffing breakdown of the National Rare Diseases Office, by grade and WTE rating; and the monetary allocation to and outturn spending of the NRDO for the period 2015–2023, in tabular form.

Dear Deputy O'Sullivan,

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.

The National Rare Diseases Office was established in 2015 following a key recommendation of Ireland's First National Rare Disease Plan 2014-2018 and governed by the National Clinical Programme for Rare Diseases (NCPRD). In 2019, the Chief Clinical Officer (CCO) published a set of recommendations following a review of all clinical programmes. The CCO recommended that once a clinical programme has become involved in the provision of service, consideration should be given to operationalising the programme. This was recommended in the case of the NCPRD, incorporating the National Rare Diseases Office. As a result, it was agreed to cease the NCPRD function and to consolidate the national rare diseases structures and resources. From 2020, the NRDO became the contact point for national HSE rare disease projects and initiatives, overseen and governed by HSE Acute Operations. The staffing breakdown of the National Rare Diseases Office is as follows:

NRDO Staffing	
Post / Grade	WTE
Clinical Lead	0.4
Business Manager Grade VIII	1.0
Information Scientist	0.6
Information Scientist	0.8
Information Scientist	0.2
Administrator Grade V	1.0
Total	4.0

With regard to the monetary allocation of the National Rare Diseases Office, it is not possible to provide this information as there is not a specific budget or spend for this office.

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

Yours sincerely,

Carol Ivory

Acting Assistant National Director, Acute Operations