

Dear

**FREEDOM OF INFORMATION – POMPE DISEASE**

I write in response to your request for information in relation to pompe disease in NHS Lothian.

**Question:**

Please provide the following data for NHS Lothian relating to Pompe disease for the period 1 October 2025 to 31 December 2025. For reference, Pompe disease may be coded under: ICD-10: E74.0 (Glycogen storage disease), or more specifically noted as Acid Maltase Deficiency / Pompe disease, SNOMED CT Concept ID: 86651009 – *Glycogen storage disease type II (Pompe disease)*

If exact matches are unavailable, please provide the nearest equivalent coding used by your Trust and specify the codes applied.

<b>Table 1 – Patients Treated and Volume used (Oct–Dec 2025)</b>		
Product	Number of Patients Treated	Volume Used (IUs or mg)
Avalglucosidase Alfa (Nexviazyme)		
Alglucosidase Alfa (Myozyme)		
Cipaglucosidase Alfa + Miglustat (Pombiliti)		

<b>Table 2 – New Patients Treated by Product (Oct–Dec 2025)</b>			
Product	January 2025	February 2025	March 2025
Avalglucosidase Alfa (Nexviazyme)			
Alglucosidase Alfa (Myozyme)			
Cipaglucosidase Alfa + Miglustat (Pombiliti)			

<b>Table 3 – Segmentation of Infantile- and Late-Onset Patients treated by product (Oct–Dec 2025)</b>				
Onset Type	Age Group	Avalglucosidase (Nexviazyme)	Alglucosidase Alfa (Myozyme)	Cipaglucosidase Alfa + Miglustat (Pombiliti)
Infantile	0–11			
	12–17			

	18+			
Late-Onset	0–11			
	12–17			
	18+			

<b>Table 4 – New Patients and switch patients by product (Oct–Dec 2025)</b>			
Product	Number of Naïve (New Start) Patients	Number of Patients Switching To this product	Number of Patients Switching From this Product
Avalglucosidase Alfa (Nexviazyme)			
Alglucosidase Alfa (Myozyme)			
Cipaglucosidase Alfa + Miglustat (Pombiliti)			

**Answer:**

This information is not held centrally. We are not able to centrally link prescribing data to diagnosis. Information may be held in individual patient records, but in order to provide the information you request it would be necessary to review each patient record over the period you have specified, requiring significant resources. Under section 12 of the Freedom of Information (Scotland) Act 2002, NHS Lothian is not required to respond to your request if the resources required to do so equate to more than £600 in cost.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at <https://www.foi.scot/appeal>. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the reviewer at the address at the top of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.



FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhslothian.scot/FOI>

Yours sincerely

**ALISON MACDONALD**  
**Executive Director of Nursing Midwifery and AHPs**  
Cc: Chief Executive