

Our Reference North East and North Cumbria ICB\
FOI ICB 25-045

North East and North Cumbria ICB
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By Email

8 May 2025

Dear Applicant

Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for your request received on 6 May 2025 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000. The ICB covers the areas of County Durham, Newcastle Gateshead, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley.

Please find the information you requested on behalf of the ICB as follows.

Your Request

1. Has your ICB developed any local planning documents, protocols or guidance specifically relating to managing pancreatic cancer enzyme replacement therapy (PERT) shortages, including but not limited to Creon, between January 2023 and present? Please respond with yes or no. If yes to question 1, please provide copies of all such documents, protocols or guidance.
2. Has your ICB procured any alternative PERT products from overseas suppliers between January 2023 and present? Please respond with yes or no. If yes to question 2, please answer the following:
 - a. Which countries were these products sourced from?
 - b. How many 'special order' prescriptions for these products have been dispensed?
 - c. What percentage of the local demand has been covered by these overseas products?
 - d. How many Trusts within your ICS have used these products?
3. Please provide details of:
 - a. Any risk assessments conducted regarding PERT / Creon shortages and;
 - b. Any monitoring systems put in place to track local supply levels, between January 2023 and present.

Please let me know if you require any further information from me to process this request.

Our Response

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB does not hold information on commissioning actions relating to PERT.

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB on this occasion is not able to provide the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested. However, we have determined that the Newcastle-upon-Tyne Hospitals NHS Foundation Trust (NuTH) has the largest cohort of patients with pancreatic cancer.

In accordance with our duty under s.16 of the FOIA to provide reasonable advice and assistance to an individual requesting information, we have provided the FOI email address for NuTH – nuth.freedom.information@nhs.net – to make your request.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Senior Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the ICB's complaints procedure.

The Information Commissioner can be contacted at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF or www.ico.org.uk.

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 www.legislation.gov.uk. This will not affect your initial information request.

Yours faithfully

Information Governance Support Officer

**Information Governance Support Officer
North East and North Cumbria Integrated Care Board**