

Our Reference North East and North Cumbria ICB\
FOI ICB 26–015

North East and North Cumbria ICB
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By Email

6 May 2026

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 14 April 2026 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

I am writing to request information under the Freedom of Information Act 2000 regarding individuals with young onset dementia (defined as individuals of any age who first experienced symptoms of dementia under the age of 65 and then received a formal diagnosis) within your local authority area.

Please provide the following information, using the most recent available data (preferably as of 14 April 2026 where possible).

Where data specific to young onset dementia as defined above is not held, please provide the closest available proxy (for example, individuals under 65 with a dementia diagnosis and note the proxy that has been used).

1. Does your ICB have a current Dementia strategy that makes specific reference to people who are diagnosed under the age 65?
2. If so, is this strategy jointly owned with your partner Local Authority/ies?

If the requested information is not held in the exact format above, please provide the closest available data.

Our Response

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested.

1. NENC ICB does not currently have a single, ICB-wide dementia strategy that specifically references people diagnosed under the age of 65 (often referred to as young-onset dementia).

Dementia is addressed within broader system plans and commissioning strategies at a high level; however, these ICB-wide documents do not include specific provision or a dedicated focus on young-onset dementia. Responsibility for detailed dementia strategies, including any specific focus on younger people living with dementia, is largely undertaken at place and local authority level.

2. This question is not applicable at ICB level, as there is no single ICB-wide dementia strategy.

However, some local authority areas within the ICB footprint do have place-based dementia strategies that explicitly address young-onset dementia. These are jointly owned with local authority partners and developed through local multi-agency arrangements.

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 contacts for local authorities in the NENC ICB region, should you wish to redirect your request.

NENC Local Authorities	Email/Online portal
Cumbria County Council	information.governance@cumbria.gov.uk
Darlington Borough Council	freedomofinformation@darlington.gov.uk
Durham County Council	Freedom of Information – Durham CC
Gateshead Council	Freedom of Information request – Gateshead Council
Hartlepool Borough Council	freedomofinformation@hartlepool.gov.uk
Middlesbrough Borough Council	Freedom of Information Request – Middlesbrough BC
Newcastle City Council	freedomofinformation@newcastle.gov.uk
North Tyneside Council	foiofficer@northtyneside.gov.uk
Northumberland County Council	Information Governance – Northumberland CC
Redcar & Cleveland Borough Council	informationgovernance@redcar-cleveland.gov.uk
South Tyneside Council	foi@southtyneside.gov.uk
Stockton-on-Tees Borough Council	foiandcomplaints@stockton.gov.uk
Sunderland City Council	freedom.information@sunderland.gov.uk

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 Information 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**