

Our Reference      North East and North Cumbria ICB\  
FOI ICB 25–427

North East and North Cumbria ICB  
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By Email

22 January 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 20 January 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**

This is a request under the Freedom of Information Act 2000. Please provide the following information held by your organisation:

1. Since 1 April 2023, the number of adults with Prader-Willi Syndrome placed in specialist residential care services where the placement has been funded wholly or partly by NHS Continuing Healthcare (CHC) or through joint funding arrangements
2. For each such placement, the gross weekly amount most recently paid for the placement, defined as the total weekly cost charged by the residential service, inclusive of accommodation (hotel), care and support.
3. Where the gross weekly amount is not held, please provide the weekly amount paid by the ICB towards the placement.

I do not require provider names, service locations, or staffing details. Individual figures may be fully anonymised. If necessary, please provide banded ranges (for example £3,000 – £6,000 per person per week).

If any part of this request exceeds the appropriate cost limit, please advise how it may be refined so that it may be answered.

## Our Response

1. NENC ICB does not record specific conditions for individuals on our CHC database – this is not a mandatory requirement and CHC is not awarded to specific conditions There are very few cases where a diagnosis is recorded (less than 5%).

However, a search of records with any diagnosis recorded found none for Prader – Willi Syndrome. This information relates to the locality teams in Durham and Darlington, Newcastle Gateshead, North Cumbria, North Tyneside, South Tyneside and Sunderland and Tees Valley. Northumberland records are held by Northumberland Local Authority.

Please note, however, that each local authority may record this information, so 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 NENC local authorities below.

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

2. Please refer to the response to question 1.
3. Please refer to the response to question 1.

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](http://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](http://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**