

05/02/2026

NN-ICB/26-1475

Dear Requestor

Re: Freedom of Information Request

Thank you for your request for information, received on 20 January 2026, regarding specialist residential care fees (Prader-Willi Syndrome). We have processed your request in accordance with the Freedom of Information Act 2000 (FOIA). Under the FOIA, public authorities like ours are required to respond to requests for information within 20 working days.

Details of your request:

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.

Our response to your request:

The ICB does not record Prader-Willi Syndrome as a discrete or searchable condition within its Continuing Healthcare (CHC) case management systems. As a result, the ICB cannot identify or extract the requested information through a report or automated search.

While it is possible that some of the requested information *may be* held within individual CHC case files, determining whether this is the case would require a manual review of each CHC-funded placement record to identify whether Prader-Willi Syndrome is referenced within clinical, assessment or placement documentation.

The ICB currently holds approximately 2,500 CHC case records that would need to be reviewed individually to determine whether they fall within the scope of your request. We estimate that this would take at least two minutes per record, equating to a minimum of 83 hours of staff time.

Under section 12(1) of the Freedom of Information Act 2000, a public authority is not obliged to comply with a request where the cost of compliance would exceed the appropriate limit. For Integrated Care Boards, the appropriate limit is £450, calculated at a rate of £25 per hour, equating to 18 hours of work, as set out in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004.

As the estimated cost of complying with your request significantly exceeds the appropriate limit, the ICB is applying Section 12 (Cost of Compliance Exceeds the Appropriate Limit) and is, therefore, unable to provide the requested information.

Advice and Assistance (Section 16 FOIA)

In accordance with section 16 of the Freedom of Information Act 2000, the ICB is able to offer advice and assistance to help you refine your request so that it may fall within the appropriate cost limit.

To reduce the scope of the request, you may wish to consider:

- limiting the request to placements initiated or active within a single recent month; or
- restricting the request to new CHC placements approved within the last four weeks.

Please note that even with a reduced timeframe, the ICB would only be able to provide information where Prader-Willi Syndrome is explicitly referenced within individual case records.

If you would like to submit a refined request on this basis, please let us know and we will be happy to consider it.

If you are unhappy with the way in which your request has been handled, NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) has an internal review procedure through which you can raise any concerns you might have. Further details of this procedure can be obtained by contacting Lucy Branson, Director of Corporate Affairs via lucy.branson@nhs.net or by writing to FOI Team at NHS Nottingham and Nottinghamshire ICB, Sir John Robinson House, Sir John Robinson Way, Arnold, Daybrook, Nottingham NG5 6DA.

If you remain dissatisfied with the outcome of the internal review, you can apply to the Information Commissioner's Office (ICO), who will consider whether the organisation has complied with its obligations under the Act and can require the organisation to remedy any problems. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Nottingham and Nottinghamshire ICB. You can find out more about how to do this, and about the Act in general, on the Information Commissioner's Office website at: <https://ico.org.uk/for-the-public/>.

Complaints to the Information Commissioner's Office should be sent to:

FOI/EIR Complaints Resolution, Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. Telephone 0303 123 1113 or report a concern via <https://ico.org.uk/concerns/>.

Yours sincerely

Freedom of Information (FOI) Officer on behalf of NHS Nottingham and Nottinghamshire Integrated Care Board nnicb-nn.foi@nhs.net

All information we have provided is subject to the provisions of the Re-use of Public Sector Information Regulations 2015. Accordingly, if the information has been made available for re-use under the [Open Government Licence](#) (OGL) a request to re-use is not required, but the license conditions must be met. You must not re-use any previously unreleased information without having the consent of NHS Nottingham and Nottinghamshire Integrated Care Board. Should you wish to re-use previously unreleased information then you must make your request in writing (email will suffice) to the FOI Lead via nnicb-nn.foi@nhs.net. All requests for re-use will be responded to within 20 working days of receipt.