

29/09/2022

NN-ICB/22/47

Dear Requestor

**RE: Freedom of Information Request**

With reference to your request for information I can confirm in accordance with Section 1 (1) of the Freedom of Information Act 2000 that we partially hold the information that you have requested. A response to each part of your request is below.

Please note that both NHS Nottingham and Nottinghamshire, and Bassetlaw Clinical Commissioning Groups ceased operation on 30 June 2022. They have been superseded by NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) which began operation on 1 July 2022.

In the request you asked:

- 1) Any treatment or policies for management of children aged 18 and under for the following conditions?  
a) PANDAS b) PANS c) immune mediated neuro behaviour conditions

Nottingham and Nottinghamshire Integrated Care Board does not hold this information. Nottingham and Nottinghamshire Integrated Care Board does not commission services that directly specify the treatment or policies that should be used for children aged 18 or under with the PANDAS, PANS or immune mediated neuro behaviour conditions. This question may be better answered by the Acute Trusts who manage the community paediatric service. This service is commissioned for the provision of a high quality, effective community paediatrics service that implements all relevant good practice guidance by clinical condition and deals with all service users holistically and across multiple agencies, as indicated to ensure health and non-health needs are addressed using a whole system approach.

For ease of reference the contact details for the acute trusts are included below:

Nottingham University Hospitals NHS Trust: [FOI@nuh.nhs.uk](mailto:FOI@nuh.nhs.uk)

Sherwood Forest Hospitals NHS Foundation Trust: [sfh-tr.foi.requests@nhs.net](mailto:sfh-tr.foi.requests@nhs.net)

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust: [d.wraith@nhs.net](mailto:d.wraith@nhs.net)

- 2) Whether there are any commissioning arrangements for children aged 18 and under for a) PANDAS b) PANS c) immune mediated neuro behaviour conditions including the details of which departments are commissioned to treat/manage these patients.

No, not specifically commissioned as a service – please see the answer to question one.

- 3) The number & costs of Independent Funding Requests (IFR's) the CCG has issued for complex childrens conditions for each for the past 5 years and whether any of these relates to a) PANDAS b) PANS c) immune mediated neuro behaviour conditions.

None.

4) Please could you provide me with any minutes of meetings which decided how patients are treated following the British Paediatric Neurology Association Consensus Statement dated April 2021 and details of any changes in how the trust treated or diagnosed patients following this statement along with details of who made the decision to implement any changes.

Nottingham and Nottinghamshire Integrated Care Board does not hold this information – please see the answer to question one.

If you are unhappy with the way in which your request has been handled, NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) have 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, Associate Director of Governance via [lucy.branson@nhs.net](mailto: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*

[notts.foi@nhs.net](mailto:notts.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 [notts.foi@nhs.net](mailto:notts.foi@nhs.net). All requests for re-use will be responded to within 20 working days of receipt.*