

25 August 2022

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Our Ref: FOI/04391

Thank you for your request concerning paediatric conditions and referrals.

Your request has been considered and processed in accordance with the requirements of the Freedom of Information (FOI) Act 2000.

**Under the freedom of information act please could you provide the following information in relation to the conditions or probably or suspected conditions in i-xiv) below?**

- i) PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)**
- ii) PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)**
- iii) Long COVID iv) immune mediated neuro behaviour conditions**
- v) neuro psychiatric conditions**
- vi) behavioural changes or altered behaviour**
- vii) sudden onset tics**
- viii) sudden onset ocd**
- iv) sudden onset eating difficulties**
- x) bodily distress disorder**
- xi) autoimmune encephalitis with an idiopathic cause**
- xii) idiopathic transverse myelitis**
- xiii) immune dysregulation**
- xiv) psychiatric disorder**

- 1. Please can you provide any**
  - a) clinical guidance**
  - b) policy**
  - c) procedure**
  - d) diagnostic pathway**
  - e) treatment pathways**
  - f) management pathway**
  - g) the clinical classification ICD-11 code or the code which would have traditionally been used if there is an absence of code for each of the conditions i)-xiv) above in paediatric patients.**

Please see attached our CAMHS Specialist Child and Adolescent Clinics Operational Policy V3.1 which outlines how referrals are received into the service and highlights the agreed pathway for child and young people who require a community CAMHS service.



2. Please could you also provide for each condition or probable/ suspected condition i)-xiv) above the number of paediatric patients presenting with these conditions for each year for the past 5 years? &
- b) how many were referred for treatment
  - c) how many referrals rejected
  - d) how many referrals were accepted
  - e) how many patients were referred to another service outside of the trust

Please could this be provided in a table format?

We are unable to help you with this question because the majority of the diagnosis identified (i)-xiv) are not indexed in the International Statistical Classification of Diseases and Related Health Problems (ICD10 5th Edition 2016), which is where we currently acquire all our classifications from.

Where possible we have provided referral numbers.

	ICD10 Code	Number of Referrals in the past 5 years	Number of Individual Service Users	Number of Referrals Accepted	Number of Referrals Declined
i) PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)	No code				
ii) PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)	No code				
iii) Long COVID	U07.4 (Post Covid)	0	0	N/A	N/A
iv) immune mediated neuro behaviour conditions	Not specific enough				
v) neuro psychiatric conditions	Not specific enough				
vi) behavioural changes or altered behaviour	Not specific enough				
vii) sudden onset tics	No code				
viii) sudden onset ocd	No code				
iv) sudden onset eating difficulties	No code				
x) bodily distress disorder	No code				
xi) autoimmune encephalitis with an idiopathic cause	No code				
xii) idiopathic transverse myelitis	G37.3	0	0	N/A	N/A
xiii) immune dysregulation	No code				
xiv) psychiatric disorder	Not specific enough				

Under Section 16 – Duty to provide advice and assistance; we are not aware that ICD11 has been implemented in England.

3. 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.

Not applicable. This would not be discussed within our Trust, we are not a paediatric neurology service.

Should you require further clarification, please do not hesitate to contact me.

Please find enclosed an information sheet regarding copyright protection and the Trust's complaints procedure in the event that you are not satisfied with the response.

Yours sincerely

*Sue Smith*

**Sue Smith**  
**Information Rights Officer**

Enc: Copyright Protection and Complaints Procedure Information Leaflet.

If you would like to complete a short survey in relation to your Freedom of Information request please scan the QR code below or click [here](#).

