

FOI REF: 22/407

26th September 2022

Tel: 0300 131 4500

Website: www.esht.nhs.uk

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

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

Further to our acknowledgement of your request, we received the following:

It it helps please could you provide the data for i) ii) iii) only? These may be coded using codes D89.89, R29.818 & U07.3.

East Sussex Healthcare NHS Trust does not use ICD-11 clinical classifications within the Trust (the coding team advise that it has not been implemented within the country yet). They have provided the ICD-10 coding for the below requested diagnoses:

- i) Pandas (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) F06.8 with B94.8 NHS digital guidelines
- ii) PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) F06.8
- iii) Long COVID =U07.4

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- 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.

The Trust does not have clinical guidance, policy, procedure, diagnostic pathway, treatment pathway, management pathway or clinical classification for PANDAS, PANS.

It would be extremely rare for a paediatrician in a DGH to be diagnosing/ managing any of these conditions in isolation and there are therefore no local pathways etc.

We would look to national guidance or guidance from tertiary centres for such cases.

The Trust do diagnose long covid but using national guidance and referral criteria.

- 2a) 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?

Using this ICD-10 coding, the Trust have no paediatric admissions/presentations for Pandas (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) or PANS (Paediatric Acute-onset Neuropsychiatric Syndrome).

Paediatric Long Covid: Zero admissions/presentations prior to 2022.

Metric	Calendar Year	Admissions	Unique Patients
Long Covid	2022	4	2

We do not record the reason/condition of a referral, therefore we are unable to provide specific data as requested above.

- 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.

We do not hold this information.

If I can be of any further assistance, please do not hesitate to contact me.

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Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

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Corporate Governance Manager
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