

Paediatric Suspected Conditions

Reference Number: F4776
Date of Response: 25/08/0222

Further to your Freedom of Information Act request, please find the Trust's response, in **blue bold text** below:

Royal Devon's Eastern FOI Office Response

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 ix) 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.

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?

Thank you for your FOI request.

The Trust has considered your request. Unfortunately, we cannot answer questions 1) and 2) for the conditions i) to xiv) listed for the following reasons: The following conditions listed: immune mediated neuro behaviour conditions, neuro psychiatric conditions, behavioural changes or altered behaviour, immune dysregulation and psychiatric disorder are huge medical umbrella terms that are not specific enough for us to answer the questions asked. For example, over the last 5 years psychiatric disorders alone involve 1000s of

CYP whose care spans primary, secondary and tertiary services with many written protocols for different conditions.

The same can be said for behavioural changes or altered behaviour.

As the questions stand, the results produced will be incomplete and therefore unreliable for interpretation. There is not a universal patient database that covers the many different pathways a patient may take i.e. RDE Hospital, Child & Family Health Devon (our CAMHS service), primary care etc. An incomplete snapshot of services will not be useful information to draw conclusions from.

12. — (1) Section 1(1) does not oblige a public authority to comply with a request for information if the authority estimates that the cost of complying with the request would exceed the appropriate limit. To answer questions 1 and 2 would exceed the appropriate cost limit as set out in Section 12 (1) of the Freedom of Information Act 2000 and is therefore exempt.

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.

The Trust does not have a standard operating procedure (SOP) for children with suspected PANDAS. We have shared the BPNA 2021 consensus statement amongst professionals within our organisation and at the time of writing, have begun discussions to develop a SOP on the basis of this consensus statement