

Freedom of Information Request

Ref: 22-390

19 August 2022

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we hold some of the information you are requesting

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.

Please see the link below for the BPNA (British Paediatric Neurology Association) Consensus Statement

https://bpna.org.uk/common/show_unpro_doc.php?doc=2021Consensusstatementonchildhoodneuropsychiatricpresentations_72d9cfce4e96a31e4f40cb3ba943cb43.pdf

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?

Please see the attached document.

& b) how many were referred for treatment

Please note, the Trust does not hold the data in a format that would enable us to fully respond

to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

c) how many referrals rejected

Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

d) how many referrals were accepted

Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

e) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?

Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

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 any minutes from meetings regarding this cohort of patients.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer
University Hospitals Bristol and Weston NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust