



Ref: FOIA Reference 2022/23-212

Royal Stoke University Hospital
Data, Security and Protection
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Date: 29th September 2022

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 16th July 2022 (received into our office 18th July) requesting information under the Freedom of Information Act (2000) regarding long Covid.

The University Hospitals of North Midlands Trust is committed to the Freedom of Information Act 2000.

However, the NHS is facing unprecedented challenges relating to the coronavirus (COVID-19) pandemic at the current time. Understandably, our resources have been diverted to support our front-line colleagues who are working tremendously hard to provide care for our patients, and to those in need of our services.

We strive to be transparent and to work with an open culture. But at this time, whilst care of our patients and the safety of our staff takes precedent, it is likely that responses to some requests for information will be delayed. We apologise for this position in advance, and will endeavour to provide you with as much information as we can, as soon as we are able.

The Information Commissioners Office has recognised the current situation in the NHS.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 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.

A1 The paediatricians at UHNM use NICE guidance and partners in paediatrics guidelines for assessment of all paediatric conditions.

NICE guidance is universally accessible to both clinicians and the general public.

Management and Investigation for each individual case, where guidance from NICE is available, is followed. Where diagnosis may be unclear MDT discussion with appropriate specialists are held to determine the best course of action.

Note: ICD-11 is not in use in the UK, below are the ICD 10 codes which best fit, particularly G04.8. These are quite generic codes and could be used to classify multiple conditions and not just the conditions listed below.

<u>Condition</u>	<u>Code</u>
Pandas (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)	There is no specific code for this condition in ICD 10, if a patient had this diagnosis we may assign the following codes depending upon the information available; <ul style="list-style-type: none"> • F42.9 Obsessive-compulsive disorder, unspecified • F95.9 Tic disorder, unspecified These codes may be assigned with B94.8 Sequelae of other specified infectious and parasitic diseases.
PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)	There is no specific code for this condition in ICD 10, the best code we have is; <ul style="list-style-type: none"> • F99.X Mental disorder, not otherwise specified
Long COVID	U07.4 Post COVID-19 condition
immune mediated neuro behaviour conditions	There is no specific code for this condition in ICD 10, the best code we have is; <ul style="list-style-type: none"> • F99.X Mental disorder, not otherwise specified
neuro psychiatric conditions	There is no specific code for this condition in ICD 10, the best code we have is; <ul style="list-style-type: none"> • F99.X Mental disorder, not otherwise specified
Behavioural changes or altered behaviour	R46.8 Other symptoms and signs involving appearance and behaviour
sudden onset tics	F95.9 Tic disorder, unspecified

sudden onset ocd	F42.9 Obsessive-compulsive disorder, unspecified
sudden onset eating difficulties	R63.3 Feeding difficulties and mismanagement R63.8 Other symptoms and signs concerning food and fluid intake
bodily distress disorder	There is no specific code for this condition in ICD 10, therefore we would assign symptom codes which could include any of the following; <ul style="list-style-type: none"> • R51.X Headache • M54.9 Dorsalgia, unspecified • M25.5 Pain in joint • M79.1 Myalgia • R06.8 Other and unspecified abnormalities of breathing • R53.X Malaise and fatigue
autoimmune encephalitis with an idiopathic cause	G04.8 Other encephalitis, myelitis and encephalomyelitis – this code could also be used to identify other specified types on encephalitis and not just autoimmune
idiopathic transverse myelitis	G37.3 Acute transverse myelitis in demyelinating disease of central nervous system
immune dysregulation	D89.9 Disorder involving the immune mechanism, unspecified
psychiatric disorder	F99.X Mental disorder, not otherwise specified

- Q2 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?**
- how many were referred for treatment**
 - how many referrals rejected**
 - how many referrals were accepted**
 - how many patients were referred to another service outside of the trust. Please could this be provided in a table format?**

A2 Unfortunately the Trust does not record on Careflow the reason why a person has been referred; nor holds information on Careflow with regards to rejected referrals. Rejected referral information is held by the national referrals system e-RS.

Please note patients are referred to a specialty/department, therefore we are unable to advise the number of referrals for specific conditions, so for example someone with suspected Long Covid will be referred to the Respiratory Department or someone with suspected neurological disorders will be referred to the Neurology department. Section 12 exemption as detailed below:

I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all individual health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all individual health records and then

extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority*

Under section 16 of the FOI Act we are required to provide requestors with advice and assistance where possible. We would therefore like to advise you that your request is shortened to just the questions that we are able to comply within the 18 hour time frame.

Q3 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?

A3 UHNM has always worked collaboratively with the Manchester neurology team regarding any patient considered to have or diagnosed with an acute neurological diagnosis. They also have strong links with the local CAMHS team should a child be presenting with both neurological and psychiatric symptoms.

Therefore no changes to practice have been identified following the issue of the BPNA consensus statement.

(Please note that this consensus statement is advisory to members of the BPNA only)
We do not hold any minutes to any meeting regarding the BPNA statement.

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,



Leah Carlisle
Head of Data, Security & Protection/ Data Protection Officer