

Information Governance

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6th September 2022

Our reference: FOI DA4293

Dear,

I am responding to your request for information received **16th July 2022**. I am sorry for the delay in responding to your request. This has been treated as a request under the Freedom of Information Act 2000.

I am now enclosing a response which is attached to the end of this letter. Please do not hesitate to contact me on the contact details above if you have any further queries.

Yours sincerely,



Shuchi Joshi
Information Governance Coordinator – Information Rights

If you are dissatisfied with the Trust's response to your FOIA request then you should contact us and we will arrange for an internal review of this decision.

If you remain dissatisfied with the decision following our response to your complaint, you may write to the Information Commissioner for a decision under Section 50 of the Freedom of Information Act 2000. The Information Commissioner can be contacted at:

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

Tel: 0303 123 1113
Web: www.ico.org.uk

Please note that the data supplied is not allowed to be re-used and/or published without the explicit consent of East London NHS Foundation Trust. Please contact the signatory to request permission if this is your intention



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Interim Chair: Eileen Taylor

Request:

Question 1: PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)
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.

h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?

i) how many were referred for treatment

j) how many referrals rejected

k) how many referrals were accepted

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

Question 2: ii) PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)
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.

h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?

i) how many were referred for treatment

j) how many referrals rejected

k) how many referrals were accepted

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

Answer: The Trust has reviewed questions 1 and 2 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
(a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
(b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust does not provide services for the treatment of PANDAS or PANS. If patients present with these conditions, we would refer them to Acute paediatrics. As such the Trust does not hold the information requested.



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- Question 3:**
- iii) Long COVID**
 - 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.**
 - h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?**
 - i) how many were referred for treatment**
 - j) how many referrals rejected**
 - k) how many referrals were accepted**
 - l) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?**

Answer: The Trust has reviewed question 3 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
(a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
(b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust does have a Long Covid clinic, however this is for adults only and is not available for paediatrics. As such the Trust does not hold the information requested.

- Question 4:**
- iv) immune mediated neuro behaviour conditions**
 - 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.**
 - h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?**
 - i) how many were referred for treatment**
 - j) how many referrals rejected**
 - k) how many referrals were accepted**
 - l) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?**

- Question 5:**
- neuro psychiatric conditions**
 - a) clinical guidance,**
 - b) policy,**
 - c) procedure**
 - d) diagnostic pathway**



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- 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.

h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?

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

Question 6: behavioural changes or altered behaviour

- 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.

h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?

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

Answer: The Trust has reviewed questions 4, 5 and 6 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
 (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
 (b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust does not provide specific services for these conditions. As such the Trust does not hold the information requested.

Question 7: sudden onset tics

- 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.



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- h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?
- i) how many were referred for treatment
- j) how many referrals rejected
- k) how many referrals were accepted
- l) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?

Question 8: sudden onset ocd

- 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.

- h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?
- i) how many were referred for treatment
- j) how many referrals rejected
- k) how many referrals were accepted
- l) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?

Answer: The Trust has reviewed questions 7 and 8 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
 (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
 (b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust does not provide specific services for sudden onset conditions, however should a patient present with these symptoms, the Trust would follow NICE guidance. There are no clinical codes for these sudden onset conditions and we do not have the information relating to the number of paediatric patients presenting with these conditions. As such the Trust does not hold the information requested.

Question 9: sudden onset eating difficulties

- 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.



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- h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?**
- i) how many were referred for treatment**
- j) how many referrals rejected**
- k) how many referrals were accepted**
- l) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?**

Answer: The Trust has reviewed question 9 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
 (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
 (b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust does not provide specific services for this condition, however should a patient present with these symptoms, the Trust would treat this symptom as part of their overall treatment plan and as such the Trust does not hold the information requested.

Question 10: bodily distress disorder

- 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.**

- h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?**
- i) how many were referred for treatment**
- j) how many referrals rejected**
- k) how many referrals were accepted**
- l) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?**

Answer: The Trust has reviewed question 10 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
 (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
 (b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust is not aware of Bodily Distress Disorder in children services as a specific condition.
 The Trust does not hold the information requested.



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Question 11: autoimmune encephalitis with an idiopathic cause

- 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.

h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?

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

Question 12: idiopathic transverse myelitis

- 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.

h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?

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

Question 13: immune dysregulation

- 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.

h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?

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



Answer: The Trust has reviewed questions 11, 12 and 13 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
(a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
(b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust does not provide services for these conditions, as such the Trust does not hold the information requested.

Question 14: psychiatric disorder
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.
h) Please could you also provide the number of paediatric patients presenting with these conditions for each year for the past 5 years?
i) how many were referred for treatment
j) how many referrals rejected
k) how many referrals were accepted
l) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?

Answer: The Trust has reviewed question 14 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
(a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
(b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust is unable to provide the requested information as the term “psychiatric disorder” is too broad. If you wish to break this down we will endeavour to respond accordingly.

Question 15: 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.

Answer: The Trust has reviewed question 15 of your request for information under the Freedom of Information Act (FOI) 2000.



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(a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and
(b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust does not hold any minutes of meetings as described in this question.



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