

Date 03/02/2015

Our reference: FOIRQ2448

Dear Ms Bond.

Please find below the information you requested under the Freedom of Information Act. In addition, as background information to this response, please find enclosed the section on FII from the Trust's "Safeguarding Children and Young People" Policy. We hope that this will help answer any queries you have on this subject and the Trust's course of action when dealing with considered and/or suspected cases of FII.

1) What are your statistics on Fabricated and Induced Illness and/or Munchausen by Proxy Syndrome cases between January 2010 and now?

On 9th January we requested the following clarification:

"Please clarify which exact statistics you require exactly?"

On 9th January you replied:

"Please provide the statistics on the following:

a) All allegations/suspicions of of FII/MBPS* which have been documented from January 2010 until current time

According to guidance provided by the National Institute for Health and Care Excellence (NICE), a case of FII/MBPS is either 'considered' or 'suspected.' The NICE definitions for "consider" and "suspect" are provided for your information: "Consider means maltreatment is one possible explanation for the alerting feature or is included in the differential diagnosis"; and "Suspect means serious level of concern about the possibility of child maltreatment but not proof of it." ²

The Trust holds no centrally recorded data on the number of considered/suspected cases of FII/MBPS or on the number of referrals to the relevant local authority where considered/suspected FII/MBPS might be a factor in the referral.

Although suspected cases would be referred to the Great Ormond Street Hospital Social Work Team, referrals to the Social Work Team are categorised and counted as:

- Child Protection
- Possible Child Protection
- Child in Need

¹ "When to suspect child maltreatment Overview: 08 September 2014" http://pathways.nice.org.uk/pathways/when-to-suspect-child-maltreatment

² Page 4, "When to suspect child maltreatment Overview: 08 September 2014"



No Action Required/No Further Action

These categories are the national requirements for collecting data, and are the same categories that local authorities use. There is no separate category for FII/MBPS.

The Social Work Team will, in consultation with other professionals, make an assessment of the concerns. If there is sufficient concern, a referral is made to the child's local authority. These concerns are not referred to local authorities as FII/MBPS but more often as medically unexplained symptoms where there is a harm consequence to the child.

In order to ascertain whether we do hold relevant information, we would have to examine the records for every social work referral for this period of time. Last month there were 21 cases referred electronically to the GOSH social work service. (There were more written and verbal referrals.) A member of the Legal Team has reviewed the Social Work Team's electronic files, looking for information about suspected/considered FII. In 30 minutes they were able to review the electronic case notes of just under three case files.

We therefore estimate that it to take at least 10 minutes to obtain each record and check for any reference to FII. Given that there were 21 electronic referrals last month, we would estimate there to be about 250 electronic referrals a year. Checking one year of referrals would therefore take (250X10)/60 = 41.7 Hours.

The Trust is therefore withholding this information under Section 12 of the Freedom of Information Act which indicates that information that would take over 18 hours to obtain is exempt from disclosure.

b) All confirmed cases of FII/MBPS* that have been documented from January 2010 until current time.

*As FII and MBPS are the same theory (MBPS being more recently referred to as FII); please group your results together."

Where investigations confirm that a child's presentation is as a result of FII, this is not centrally recorded.

Insofar as the Trust holds relevant information, the answer to this question is the same as the answer to Question 1(a) above. (The Trust may not have this information if care of the patient has been transferred to another authority.)

2) How many of these cases have since been proven to be organic clinical/genetic conditions and not child protection issues?

Where investigations indicate that organic/clinical issues caused the concerning presentation, this is not centrally recorded.

The fact that a concerning presentation is shown to result from an organic clinical/genetic condition does not in itself rule out the possibility of child protection issues.

3) What is Dr Danya Glaser's role in your Trust and her key responsibilities?

Dr Glaser is an Honorary Consultant Child and Adolescent Psychiatrist. Dr Glaser's current role in the Trust is Chair of the Gastroenterology Complex Multidisciplinary Team, which meets weekly. Her responsibility is to coordinate information about the children discussed and consult to the responsible clinicians on management of the children. Her role is consultative and she has no direct patient responsibility. Dr Glaser is also called upon to consult on the management of children in other specialities whose presentation is perplexing.

4) Where is Dr Danya Glaser's control group based for her research into spotting the early symptoms of FII?

Dr Glaser has not been and is not carrying out a formal research study into spotting the early symptoms of FII.

Dr Glaser has compiled a list of alerting signs which have been published and used widely, including in a paper which she co-authored in the Lancet in May 2014. This list was drawn up about 15 years ago. It was not tested against a control group; it was based on clinical experience.

5) How many wrongly-accused parents have received a full apology from your Trust after being cleared of FII/MBPS?

To clarify, a concern or suspicion of FII is part of a clinical differential explanation for a child's difficulty and should not be seen as an accusation against the parents or anyone else.

When an alternative explanation for a child's condition is established, this explanation about the child's difficulties would naturally be given to the parents.

We do not have centrally recorded information on this point. Relevant information may be held in the Social Work electronic files; however as detailed above, the estimated time taken to retrieve this information would exceed 18 hours and is therefore exempt from disclosure under Section 12 of the Freedom of Information Act.

6) Why are so many parents suddenly accused of FII/MBPS when they complain about poor clinical care by one of your employees?

As explained above, concern or suspicion of FII is part of a clinical differential explanation for a child's difficulty and should not be seen as an accusation against the parents or anyone else

One common feature of FII is erroneous reporting of signs and symptoms, which may include fabrication and/or exaggeration of past medical history.



This reporting can include complaints about a child receiving insufficient medical treatment. It does not follow from this that parents/carers who complain are automatically suspected or considered of FII.

The Complaints team aims to ensure that patients, relatives and their carers are not treated differently as a result of a complaint. As a means of ensuring this, the complaint correspondence and the patient's medical records will be kept separate and the complainant will be assured of this when their complaint is acknowledged.

The Complaints team will send a survey to all complainants as appropriate, when the complaint is closed, asking whether or not they feel that they have been treated differently as a result of them having raised a complaint. The results will be made available in the complaints annual report to the Clinical Governance Committee (CGC) and Learning Implementation and Monitoring Board (LIMB). Should any individual report that they have been treated adversely since raising a complaint, attempts will be made to resolve this locally. Local resolution may include business managers, general managers, divisional directors, the Medical Director, Chief Executive or any other relevant party as is deemed appropriate by the Patient Safety and Complaints Manager.

7) Are the complaints of these parents re-investigated and appropriate disciplinary action taken once parents are cleared of FII/MBPS and an organic clinical/genetic diagnosis given to the child?

The Trust takes all complaints seriously. Any complaint by a parent/carer is fully investigated. If additional information comes to light following the completion of a complaints process, the investigation may warrant a further referral to/for:

- An investigation under the disciplinary procedure;
- One of the professional regulatory bodies;
- A serious incident investigation (SI); or
- An investigation of a criminal offence

The complainant will be advised of the procedure being followed.

Unfortunately it is known that some parents/carers do harm children. It is an appropriate part of child safeguarding procedures (which are an integral part of good paediatric practice) to raise concerns about possible harm (whether as a result of FII or otherwise) so that these can be investigated. As this is part of Trust policy, it would not be a disciplinary matter if a member of staff raised safeguarding concerns, even if the concerns are subsequently able to be dismissed.

8) Why do you heavily edit the medical notes released to parents under FOI requests on behalf of their children after parents have complained about poor care?

The Trust does not release patient records under the Freedom of Information Act (FOIA). The Data Protection Act 1998 gives a person the right to access personal information about themselves (or, in certain circumstances, their children). So, if a parent asks for the medical records of their child, this request will be considered under the Data Protection Act.

Prior to release of such patient records to a patient/parent/third party with consent, the records will be reviewed by the patient's lead consultant who consents to the release of the records.

The fact of a prior complaint does not influence the information that is released following a request for medical records.

I trust that the information provided is sufficient and helps to answer any concerns, questions or issues you may have.

If you should have any further queries related to this request, please do not hesitate to contact me. Please ensure that the above reference number is quoted on any correspondence.

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Yours sincerely

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[enclosed – Your rights – see next page]



Your rights

If you are not satisfied with the response to your request for information, please do not hesitate to contact the member of the FOI team whose name appears on the response letter. Please quote your reference number on any correspondence.

You can also write to the Head of Clinical Governance & Safety at the following address:

Clinical Governance & Safety Team Great Ormond Street Hospital LONDON WC1N 3JH

If you are still not satisfied with your response, you also have the right to appeal to the Information Commissioner.

You can contact the Information Commissioner's Office at the following address:

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