

Date: **20 November 2019**

Our reference: **FOIRQ5178**

Dear Sir/Madam,

Thank you for your request for information processed under the Freedom of Information Act 2000. Please see our response to your request below:

Your Request

Please would you provide the following information:

1) *the number of deaths of patients with a learning disability that occurred in the last three years (by years defined as 1/4/16 - 31/3/17, 1/4/17 - 31/3/18, 1/4/18 to present).*

2) *the number of deaths of patients with a learning disability reported as an incident on the National Reporting and Learning System (NRLS) in the last three years (defined as above)*

3) *the number of deaths of patients with a learning disability reported as an incident on the Strategic Executive Information System (STEIS) in the last three years (defined as above)*

Our Request for Clarification

Please can you clarify the following points?

Can you please confirm in respect of the information you require, are you requesting information that is specific to Great Ormond Street Hospital or are you requesting information that is NHS-wide.

Your Response to Our Request for Clarification

I am interested in all deaths of patients with a learning disability that you are aware of. If you wish to delineate that information to provide inpatient and community patient data that would be welcome, but I would like it in relation to inpatients at the very least.

Our Response (in bold)

1) *the number of deaths of patients with a learning disability that occurred in the last three years (by years defined as 1/4/16 - 31/3/17, 1/4/17 - 31/3/18, 1/4/18 to present).*

Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is a single site, specialist tertiary paediatric trust. The 'National Guidance on Learning from Deaths' recognises The Learning Disabilities

Mortality Review (LeDeR) programme as an established methodology for the reviewing of deaths of patients with learning disabilities, and requires that *'All deaths of people with learning disabilities aged four years and older are subject to review using LeDeR methodology'*.

The guidance recommends that providers notify LeDeR of the deaths of children with a learning disability (aged 4yrs+). The GOSH Mortality Review Group (MRG) is a multidisciplinary group of senior clinicians that conducts routine and independent structured case record reviews of all deaths that occur at GOSH. The MRG has been in place since 2012.

The Trust is able to provide the number of deaths reviewed via our MRG where the patient had a diagnosis of a learning disability aged four or above (as per the LeDer requirement) covering financial year 2016/17 up to the date your request was received on 12/04/2019. We have identified 15 inpatients deaths via the MRG as having a learning disability in line with the LeDer reporting guidance.

Please note 1: The data is around patients who died at GOSH and not gosh patients by the point of registration. See note below**]

Please note 2: **The Trust is unable to respond to information in the format of a breakdown for each financial year requested as there were fewer than five data subjects (<5). Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is withholding this information under Section 40 (Personal Information) of the Freedom of Information Act (FOIA) 2000 in order to reduce the risk of identifying an individual. The Trust's view is that in providing this information it would significantly increase the risk of individuals being identified.

The Trust believes that Sections 40(2) of the FOIA is applicable in withholding the information as disclosure could lead to individuals being identified; which is considered to be a breach of their rights under the Data Protection Act (DPA) 2018. The grounds for applying this exemption are as follows:

- In the context of your request, this data is third party information. The Trust categorises the information about our patients' health as information falling within paragraph (e) of the definition of "sensitive personal data" in s.2 of the DPA 2018. As such, Section 40(2) of the FOIA applies to this information, as does the Trust's duty of confidentiality. Therefore under s.2(3)(f)(ii) of the FOIA, there is an absolute exemption from disclosure on the grounds that it would contravene the First Data Protection Principle.

- The Trust has a duty under the DPA 2018 and the First Data Protection Principle to process personal data regarding the Trust's patients fairly and lawfully and, in particular, not process data unless at least one of the conditions in Schedule 2 DPA is met, and in the case of sensitive personal data, at least one of the conditions in Schedule 3 DPA is also met.
- The Act has defined "sensitive personal data" to include data on the "physical or mental health or condition" of a person (s.2(e) DPA). Any medical information about specific individual falls within this category and disclosure of this data to a FOI applicant would be processing sensitive personal data of those patients.

In line with the guidance from the Information Commissioner's Office based upon the requirements of the Data Protection Act the Trust has considered first whether it would be "fair" to process and disclose the requested information, and whether it would be lawful to disclose the requested information before considering whether any Schedule 2 and Schedule 3 conditions have been met. Disclosing medical information to the public regarding the Trust's patients is likely to lead to emotional distress of the patients and their families. It is also the Trust's position that there is a reasonable expectation on the part of the Trust's patients and their families that their sensitive personal data would not be disclosed to FOI applicants.

A breach of this expectation would have the effect of the data being processed unfairly. The information that forms part of the medical records of an individual is therefore implicitly confidential. The courts and the Information Commissioner have long recognised the strong public interest inherent within keeping confidential medical information confidential. The Trust holds the view that Section 41 (1) of the FOIA is applicable for the reasons that: the information was obtained by the Trust; it has the necessary quality of confidence (being neither generally accessible nor trivial); and disclosure of this information to an FOI applicant would give rise to an actionable breach of confidence.

2) the number of deaths of patients with a learning disability reported as an incident on the National Reporting and Learning System (NRLS) in the last three years (defined as above) 1 death from the above data was reported on both the NRLS and STEIS covering the period of time requested (up to the date your request was received on 12/04/2019.

3) the number of deaths of patients with a learning disability reported as an incident on the Strategic Executive Information System (STEIS) in the last three years (defined as above) Please see our response above to Q.2.

Please note:

The information provided under the Freedom of Information Act 2000 is the information held on the date the request was received by the Trust.

I trust 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 the FOI Team. Please ensure that the above reference number is quoted on any correspondence.

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Yours sincerely

Freedom of Information team

Great Ormond Street Hospital for Children NHS Foundation Trust

Email: foiteam@gosh.nhs.uk

[Enclosed – Your rights – see next page]

Your Rights

If you are not dissatisfied with the response you have received to your request for information, please contact the FOI team and quote your reference number on all correspondence relating to your request.

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

Quality & 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