

Date: 17 October 2017
Our reference: FOIRQ3969

Dear Sir/Madam,

Please find below the information you requested under the Freedom of Information Act.

Your Request:

1. *Can GOS confirm that the Charlie Gard was seen by a specialist ophthalmologist and confirmed blind?*
2. *Can GOS confirm that Charlie Gard was seen by an audiologist and confirmed Deaf?*
3. *Can GOS confirm how they measure pain in patients that are non verbal?
Judith Middleton asked for this information.*
4. *Can GOS confirm that pain was present in the case of Charlie Gard?*
 - 4a. *Can GOS confirm Charlie has/is/was being treated for pain?*
5. *Can GOS give reasons that all measurements of Charlie Gard's EEG scan were not included in an email to the US specialist?*
6. *Can GOS confirm that all MRI, EEG and all other types of scans were sent with full detail to the US specialists, giving true presentations to his condition?*
 - 6a. *Can GOS confirm that the private sector had refused Charlie's treatment because "they didn't want to step on toes" of GOS staff, and that had the court appeal succeeded they would have accepted Charlie Gard as a patient?*
7. *Can GOS confirm that the ventilation Charlie Gard is on is a temporary measure and a tracheostomy could instead be fitted, allowing Charlie Gard to live?*
8. *How much would tracheostomy care cost GOS annually for Charlie Gard?*
9. *How many patients are fitted with a tracheostomy?*
 - 9a. *How many patients are fitted with one who have mitochondrial depletion syndrome?*
 - 9b. *How many patients with mitochondrial depletion syndrome have been treated by GOS?*
10. *How many experts are experienced in nucleosides?*

11. *Has Charlie made any improvement in his ten months of life?*

12. *If unsuccessful in the European Courts can GOS confirm who will be the person responsible for turning off Charlie Gard's Ventilator?*

13. *Can GOS confirm there is/was no possibility of life, compared to other severely disabled patients who suffer the same/more severe complicating illnesses?*

Our Response:

Questions 1, 2, 4, 5, 6, 7, 11 and 13

Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is unable to respond to certain elements of your request. The Trust considers the response to questions 1, 2, 4, 5, 6, 7, 11 and 13 to be exempt under s.40(2) of the Freedom of Information Act 2000 (FOIA). This is due to the fact that the information you have requested contains medical information and medical history of a patient at the Trust.

The grounds for exemption of this information 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 Data Protection Act 1998.

As such s.40(2) FOIA applies to this information, as does the Trust's duty of confidentiality, and therefore under s.2(3)(f)(ii) FOIA there is an absolute exemption from disclosure on the grounds that it would contravene the First Data Protection Principle. The First Data Protection Principle states that: Personal data shall be processed fairly and lawfully

Information that forms part of the medical records of an individual is 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 s.41(1) applies because the information was obtained by the Trust; 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.

Question 3

A significant proportion of patients at Great Ormond Street Hospital are unable to use self-report pain assessment tools for a number of reasons including patients such as neonates and infants who due to age are unable to self-report, patients in an intensive care setting that may be intubated or sedated and patients with severe cognitive impairment. In these non-verbal children

validated pain assessment tools are used that utilise a combination of behavioural cues and physiological signs to make an assessment of a child's pain intensity. The current tools utilised for children unable to self-report at GOSH include the following:

Neonatal Pain Assessment Tool (PAT) - is a behavioural/physiological tool designed for use with neonates in either an intensive care setting or on a ward;

FLACC - is a behavioural assessment tool utilised in children from 2 months of age to 7 years;

Revised FLACC- is a behavioural tool designed for use with children with cognitive impairment, this tool can be individualised;

COMFORT- is a behavioural/physiological tool designed for assessing pain in ventilated and sedated children in an intensive care setting.

Question 6a

The Trust does not hold this data and is unable to answer this question.

Question 8

The Trust considers medical costs associated with Charlie Gard's care at the Trust to be exempt under s.43 of FOIA.

The Trust has reached the view that information relating to local rates and prices for procedures is commercially sensitive. Each trust negotiates rates separately with NHS England and this financial information is not shared widely. Sharing this information would allow suppliers to adjust their pricing and would compromise the Trust's ability to obtain value for public money. This would prejudice the Trust's commercial interests; therefore the requested information is exempt under s.43 FOIA.

S.43 is a qualified exemption, and the Trust has conducted a public interest test to weigh the public interests for and against disclosure.

The Trust acknowledges that disclosing this information would demonstrate the Trust's commitment to transparency, however in this instance disclosing the requested information, in so far as it relates to Charlie Gard's medical costs, is deemed to be exempt.

Question 9, 9a and 9b

The scope of this question is too wide. Could you kindly provide a time frame for the information requested, for example from 01.01.2014 to 31.12.2016?

Question 10

This is a rare and emerging area in medicine. Clinicians at GOSH engage internationally with other world experts in many areas of medicine and therapy to ensure that the Trust remain at the forefront of great medical breakthroughs and therapies.

Question 12

The Trust is unable to provide a detailed answer to this question as the information requested falls within paragraph (e) of the definition of “sensitive personal data” in s.2 of the Data Protection Act 1998 and is therefore exempt under s.40(2) FOIA. However based on information available in the public domain, the Trust is able to confirm: on 27th June 2017 the European Court of Human Rights declared the application made by the parents of Charlie Gard inadmissible. Charlie Gard was transferred to a hospice on 27th July 2017.

Please note:

The information provided under FOI is information held at the date on which the request was made.

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

Freedom of Information team

Great Ormond Street Hospital for Children NHS Foundation Trust
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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 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