

Date: 11 July 2019

Our reference: FOIRQ5286

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 and Our Response (in bold)

Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is a single site, specialist tertiary paediatric trust. Please see our response to your following request for information:

Please list the number of people between 2011 and 2018 to have died in your hospitals after being placed on end-of-life care which resulted in a DNAR order being introduced. Please break down the figures year by year.

GOSH patients are not 'placed on end of life care'. We do not place patients on an 'end of life care pathway'. We use treatment escalation plans (emergency care plans) to agree with families (and the child/young person where appropriate) the level of treatment escalation as appropriate.

A referral to palliative care would not mean the child is on an 'end of life pathway' and many of the children referred to palliative care remain for treatment escalation, including resuscitation. Within the Trust a number of children who died had a limitation of escalation decision. The Trust only has recorded date going back as far back 2015 as follows:

Calendar Year	Inpatient deaths	Number of deaths where the Trust Mortality Review Group have indicated that a DNAR was in place
2015	103	56
2016	86	55
2017	110	75
2018	86	60

Please list the number of DNAR orders issued by your hospitals each year between 2011 and 2018. Please break down the figures year by year.

The Trust does not maintain a central record of the number of treatment escalation plans made with families; nor the number of these that result in a decision not to resuscitate (ie a DNAR order). A DNAR is not a one-way process; but where such plans exist they remain flexible and the decision may be reversed over time; or at the point of hospital discharge or admission. This is not a single point decision-making process and rather an evolving and changing decision-making process; based on a changing clinical situation. In going forward to start centrally recording this information, including where decisions are reversed, we cannot provide the number of DNAR orders for the period you have requested from 2011-2018. Please see note below**

Please Note: **The Trust is unable to respond to your request for information as DNAR orders are not centrally recorded information. DNAR orders are most likely to be held within individual patient records and would, therefore, require individual enquiries to be carried out of the systems and patient records held across various departments within the Trust. Even to reduce the time period, ie, last calendar year, it would still mean having to contact all the departments prior to carrying out the same individual searches of thousands of patient records. We have estimated that to carry out initial enquiries and conducting the level of searches would most certainly exceed the 18 hour cost limit; which is the limit for processing requests for information under Section 12 of the Freedom of Information Act (FOIA) 2000.

Section 12(1) (Cost Limit) of the Freedom of Information Act (FOIA) 2000 allows the Trust to refuse a request where the cost of compliance is estimated to exceed the appropriate limit. The appropriate limit for section 12 purposes is defined by The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 SI 2004 No 3244 ('Fees Regulation').

Under regulation 3 of the Fees Regulation the appropriate cost limit for the Trust is £450. The Fees Regulation also states that all authorities should calculate the time spent on the permitted activities at the flat rate of £25 per person, per hour. This means that the appropriate limit will be exceeded, if it would require more than 18 hours' work for the Trust to carry out the following activities in complying with the request:

- **determining whether the information is held**
- **locating the information, or a document containing it;**
- **retrieving the information, or a document containing it; and**
- **extracting the information from a document containing it.**

Please list the number of complaints your hospitals have received over the introduction of DNAR orders between 2011 and 2018. Please break down the figures year by year. Please provide as much detail as possible on what was being complained about.

Please see our response in the following table on the number of formal complaints received over the introduction of DNAR orders between 2011 and 2018:

Year	Number of formal complaints
2013	1
2014	1
2016	1
2018	2

Please note: All 5 formal complaints above raised concerns that DNAR was suggested or introduced.

Please note:

The information we have provided under the Freedom of Information Act 2000 is the information held up to the date your request was received by the Trust.

We trust the information provided is sufficient and helpful in answering your request for information. If, however, you have any queries in relation to your request, please do not hesitate to contact the FOI Team and quote the above reference number on any related 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 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