

Date: **13 August 2019**

Our reference: **FOIRQ5338**

Dear Sir/Madam,

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

**Your Request**

*I would like to make a Freedom of Information Request via the FOI Act from NHS England. I would like answers to the following questions:*

*Does this hospital trust currently treat Systemic Scleroderma (also known as Systemic Sclerosis/ Diffuse Scleroderma)?*

*If the trust does treat Systemic Scleroderma, at what sites does the treatment occur?*

*If the trust does treat Systemic Scleroderma:*

*If possible, I would like the yearly data for 2015, 2016, 2017 and 2018 for patient treatment, broken down by age (children and adults).*

*However, if this breakdown is not possible, I understand and normal treatment numbers will suffice*

**Our Response**

Great Ormond Street Hospital for Children NHS Foundation Trust (“the Trust”) is a single site, specialist tertiary paediatric trust. The treatment for Systemic Scleroderma is undertaken at the Great Ormond Street Hospital. We do not centrally record this information, however, we have carried out a search via our Information Services for analysis on the basis of all patients, who had a Diagnostic Date greater than or equal to 01/01/2015 and less than equal to 31/12/2018.

Please note: The Diagnosis Date: is the date the diagnosis was coded (Code\_Date); when the Code\_Date is within the *episode start* and *episode finish* date; or the *episode end date/episode start* date when the Code\_Date is outside the *episode start and finish* dates.

Please see the total number of unique patients treated for Systemic Scleroderma in the following table; which is broken down by calendar year only:

Calendar Year	Total Patients
2015	11
2016	17
2017	16
2018	22

**Note:** The Trust can only provide the total number of patients diagnosed per calendar year where there has been 5 and above number of patients; but where you have specified a breakdown 'by age of patient' the outcome of the analysis has returned a result of 5 or less patients within each age group within the figures provided for each calendar year above. **Please see the following note to explain our reason for withholding the breakdown of information you have requested\*\***

**Please note:** \*\*The Trust is unable to provide a breakdown of the information 'by age of patient' where there has been being fewer than five data subjects (<5) per age group within the total number per calendar year. 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 is of the view that disclosure of information would significantly increase the risk of individuals being identified and would therefore constitute a breach of their personal data.

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.

Please note:

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

We trust the information provided is sufficient and helped to answer any issues, concerns or questions. Should you have any further queries in relation to this 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](mailto: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