



Ref: FOIA Reference 2019/20-062

Date: 13<sup>th</sup> May 2019

Email [foi@uhnm.nhs.uk](mailto:foi@uhnm.nhs.uk)

Dear

I am writing in response to your email dated 30<sup>th</sup> April 2019 requesting information under the Freedom of Information Act (2000) regarding Worster Drought Syndrome.

I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in your questions is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for.

As of 1<sup>st</sup> November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

**Q1 Worster Drought Syndrome is a rare/ultra-rare disease that in 2019 Orphanet estimate to have a European prevalence of 3.7 cases per 100,000 population.**

**Based upon this prevalence there are estimated to be 2,442 patients however some prevalence estimates are 9 in 100,000 population with up to 5,940 prevalent population in the UK today.**

**There is concern that WDS is under-diagnosed or misdiagnosed, there does not appear to any treatment pathway or recommendations for the referral, management or identifiable specialist centres for diagnosis and management in the UK.**

**There is not a specific ICD 10 code available to attribute to a WDS diagnosis, as a form of cerebral palsy (ICD10 G80). WDS is then included in the sub categories C80.8 (Other Cerebral Palsy) or C80.9 (Cerebral Palsy Unspecified)**

**The table below outlines the data that the WDSSG would like to know.**

|  | Number<br>M/F | Age at<br>diagnosis | ICD 10<br>code | Other co-<br>morbidities<br>and ICD |
|--|---------------|---------------------|----------------|-------------------------------------|
|  |               |                     |                |                                     |

|  |  |  | applied | codes |
|--|--|--|---------|-------|
| A primary diagnosis of Worster Drought over the last 3 years                                       |  |  |         |       |
| Worster Drought prevalence (all ages) under your care  |  |  |         |       |
| No of patients diagnosed with Congenital suprabulbar palsy/paresis                                 |  |  |         |       |
| No of patients diagnosed with Congenital pseudobulbar palsy/paresis                                |  |  |         |       |
| No of patients diagnosed with bilateral perisylvian polymicrogyria                                 |  |  |         |       |
| No of patients diagnosed with foix-chavany-marie syndrome  |  |  |         |       |
| How many patients have had a diagnosis of WDS which has been re coded: to what disease/ICD10 code? |  |  |         |       |
| How many patients have been re coded to WDS  |  |  |         |       |
| Any specific specialities/services/pathways/recommendations provided for WDS patients              |  |  |         |       |

A1 Section 12 exemption as detailed above.

\*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

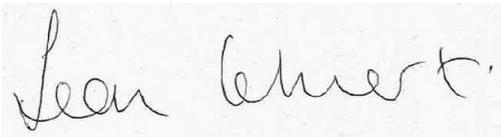
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via [www.ico.org.uk](http://www.ico.org.uk).

If following review of the responses I can be of any further assistance please contact my secretary on 01782 676474.

Yours,



Jean Lehnert  
**Information Governance Manager**