

Information Governance

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Date Received: 30th April 2019

Response Due: 30th May 2019

3rd June 2019

Dear

INFORMATION REQUEST UNDER THE FREEDOM OF INFORMATION ACT 2000

You asked:

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 population¹.

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.

The WDSSG are attempting to identify where diagnosis is taking place, the diagnosed prevalence of WDS and for potential similar syndromes/diseases where there could be misdiagnosis or no diagnosis at all in order to work with the NHS to provide education and hopefully better outcomes for patients.

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 M/F	Age at diagnosis	ICD 10 code applied	Other co- morbidities and ICD 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				

The Trust is unable to provide this data as it is not recorded centrally, if recorded it would be held within individual case notes. It would not be possible to identify individuals without reviewing case notes for all patients coded with cerebral palsy. As case notes are for the care and treatment of patients we do not ask staff to scrutinise them in order to respond to Freedom of Information requests.

I trust that this information is helpful to you, however if you are not entirely satisfied with this response please do not hesitate to contact the Information Governance Department on 01257 488271. If we do not hear from you within 28 days we will assume that we have been able to accommodate your request under the Freedom of Information Act 2000.

Yours sincerely,



Rob Forster
Deputy Chief Executive/Director of Finance

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If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you should write to: Information Governance Department, Wrightington, Wigan and Leigh NHS Foundation Trust, Wrightington Hospital, Hall Lane, Appley Bridge, Wigan, WN6 9EP

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner for a decision. Generally the ICO cannot make a decision unless you have exhausted the complaints procedure at: The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF