

Date: 15/05/2019

FREEDOM OF INFORMATION REQUEST 014781 - Worster Drought Syndrome

I am making this Freedom of Information request of the Worster Drought Syndrome Support Group (WDSSG <http://www.wdssg.org.uk/>).

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)

As there is no specific code for Worster Drought Syndrome the Trust is unable to determine from coding alone what the condition is. A review of patient notes is the only way to determine this specific condition but patient notes are not accessible under the FOI Act.