

Severe acute porphyria service (All Ages) 2020/21



Indicator Reference Number	Domain	Theme	Measure	Rationale	Name of Indicator/KPI	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Interpretation Guidance	Notes	Reporting Periods			
															Q1	Q2	Q3	Q4
E06/S(HSS)/e-19-101	Domain 1: Preventing people from dying prematurely	Clinical outcome	Mortality		Mortality rate	Of those in the denominator, the number of patients who died	Active caseload in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
E06/S(HSS)/e-19-102	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Frequent admissions		Proportion of patients having 4 or more hospital admissions (porphyria-related) in the previous 12 months	Of those in the denominator, the number of patients having 4 or more hospital admissions (porphyria-related) in the previous 12 months	Active caseload in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21

Data collection has been approved by the Review of Central Returns - ROCR
ROCR/OR/2230/001MAND