

Atypical haemolytic uraemic syndrome (aHUS) (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
170008/S-19-101	Domain 1: Preventing people from dying prematurely	Outcome measure	Mortality		Proportion of deaths in patients with a diagnosis of complement mediated aHUS	Of those in the denominator, the number of deaths in patients with a diagnosis of complement mediated aHUS	Total number of patients in the reporting period	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
170008/S-19-102	Domain 1: Preventing people from dying prematurely	Outcome measure	Time to treatment		Average length of time from referral to treatment	For those patients starting treatment, the total sum of time (in days) from referral to start of treatment	Total number of patients starting treatment in the reporting period	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
170008/S-19-103	Domain 1: Preventing people from dying prematurely	Outcome measure	Transplantation		Proportion of eligible patients listed for renal transplant	Of those in the denominator, the number who are listed for renal transplant	Total number of patients eligible for renal transplant in the reporting period	Annual	Annual	Provider Submitted	Provider Submitted		Neutral		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