

Paroxysmal Nocturnal Haemoglobinuria Service (Adults and Adolescents) 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
B05/S(HSS)/a-19-101	Domain 1: Preventing people from dying prematurely	Outcome measure	Survival rate		5-year relative survival rate	Of those in the denominator, the number of patients alive 5 years post treatment	Number of patients treated in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	of those patients who had treatment in 2015/16, how many are alive in 2020/21	N/A	N/A	N/A	Apr 15 to Mar 16
B05/S(HSS)/a-19-102	Domain 2: Enhancing quality of life for people with long-term conditions	Outcome measure	Transfusion rate		Median transfusions per patient in previous 12 months	Active caseload	N/A	Annual	Annual	Provider submitted data	N/A		Higher 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