

Epidermolysis bullosa 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
A12/S(HSS)/a-19-101	Domain 2: Enhancing quality of life for people with long-term conditions	Outcome measure	QoLEB score		Median quality of life score at transition (QoLEB)	Median quality of life score at transition (QoLEB)	N/A	Annual	Annual	Provider Submitted	N/A		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
A12/S(HSS)/a-19-102	Domain 2: Enhancing quality of life for people with long-term conditions	Outcome measure	Unplanned admissions		Proportion of unplanned admissions among patients with RDEB	Of those in the denominator the number of unplanned admissions among patients with RDEB	Active caseload of patients with RDEB in the reporting period	Annual	Annual	Provider Submitted	Provider Submitted		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