

Alkaptonuria service (Adult) 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)/a-19-103	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical Outcome	SF36 score		Median SF36 score The median score for the general health domain of SF 36 for English and Scottish patients treated with NTBC over the course of the reporting year	Active caseload (include both English and Scottish patients treated with NTBC)	N/A	Annual	Annual	Provider submitted	N/A		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
E06/S(HSS)/a-19-104	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical Outcome	AKU Severity score		Median AKUSSI score Reporting the AKUSSI median score for English and Scottish patients treated with NTBC over the course of the reporting year.	Active caseload (include both English and Scottish patients treated with NTBC)	N/A	Annual	Annual	Provider submitted	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