

Complex Ehlers Danlos 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
A13/S(HSS)/b-19-101	Domain 2: Enhancing quality of life for people with long-term conditions	Outcome measure	Diagnosis		Proportion of patients with a definitive diagnosis or diagnosis ruled out	Of those in the denominator, the number of patients with a definitive diagnosis or diagnosis ruled out	Number of new patients in the reporting period	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
A13/S(HSS)/b-19-102	Domain 2: Enhancing quality of life for people with long-term conditions	Outcome measure	Genetic diagnosis		Proportion of patients with a genetic diagnosis	Of those in the denominator, the number of patients with a genetic diagnosis	Number of new patients 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