

Barth Syndrome Service (All Ages) 20/21



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)b-19-101	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Diagnosis age		Median age at diagnosis	Median age at diagnosis	N/A	Annual	Annual	Provider Submitted	N/A		Lower is Better		Apr 19 - Mar 20	N/A	N/A	N/A
E06/S(HSS)b-19-102	Domain 1: Preventing people from dying prematurely	Clinical outcome	Mortality		Median age at death	Median age at death	N/A	Annual	Annual	Provider Submitted	N/A		Higher is Better		Apr 18 - Mar 19	N/A	N/A	N/A
E06/S(HSS)b-19-104	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Infections		Proportion of of hospital admissions for bacterial infections for patients on G-CSF	No. of patients receiving G-CSF	No. of patients with neutropenia	Annual	Annual	Provider Submitted	Provider Submitted		Higher is Better		Apr 19 - Mar 20	N/A	N/A	N/A
E06/S(HSS)b-19-105	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Infections		Proportion of hospital admissions for bacterial infections for patients on G-CSF	Number of patients on G-CSF admitted for bacterial infections	No. of patients on G-CSF	Annual	Annual	Provider Submitted	Provider Submitted		Lower is Better		Apr 19 - Mar 20	N/A	N/A	N/A

Data collection has been approved by the Review of Central Returns - ROCR
ROCR/OR/2230/001MAND