

Lysosomal storage disorders 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
E06/S(HSS)/c 19-101	Domain 2: Enhancing quality of life for people with long-term conditions	Fabry patients	Clinical outcome		Proportion of Fabry patients initiating renal replacement therapy among patients treated for 3 years or more	Of those in the denominator, the number of patients initiating renal replacement therapy	Active caseload Fabry patients treated for 3 years or more	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20 Mar 21
E06/S(HSS)/c 19-102	Domain 2: Enhancing quality of life for people with long-term conditions	Fabry patients	Clinical outcome		Proportion of Fabry patients having a new stroke among patients treated for 3 years or more	Of those in the denominator, the number of patients having a new stroke	Active caseload Fabry patients treated for 3 years or more	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 Mar 21
E06/S(HSS)/c 19-103	Domain 2: Enhancing quality of life for people with long-term conditions	Fabry patients	Clinical outcome		Proportion of Fabry patients having a cardiac device implanted among patients treated for 3 years or more	Of those in the denominator, the number of patients having a cardiac device implanted	Active caseload Fabry patients treated for 3 years or more	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20 Mar 21
E06/S(HSS)/c 19-104	Domain 2: Enhancing quality of life for people with long-term conditions	Gaucher patients	Clinical outcome		Proportion of Gaucher patients having a hospital admission for bone crisis among patients treated for 3 years or more	Of those in the denominator, the number of patients having a hospital admission for bone crisis among patients treated for 3 years or more	Active caseload Gaucher patients treated for 3 years or more	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 Mar 21
E06/S(HSS)/c 19-105	Domain 2: Enhancing quality of life for people with long-term conditions	MPS patients	Clinical outcome		Proportion of MPS patients having a new cranio cervical episode among patients treated for 3 years or more	Of those in the denominator, the number of patients having a new cranio cervical episode among patients	Active caseload MPS patients treated for 3 years or more	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 Mar 21
E06/S(HSS)/c 19-106	Domain 3: Helping people to recover from episodes of ill health or following injury	Referral	Clinical outcome		Proportion of patients seen within 48 hours of an emergency referral	Number of patients seen within 48 hours of being referred	Number of emergency referrals in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20 Mar 21
E06/S(HSS)/c 19-107	Domain 3: Helping people to recover from episodes of ill health or following injury	Referral	Clinical outcome		Mean length of time from referral to commencement of definitive treatment as defined in the service specification	Total (sum) length of time from referral to commencement of definitive treatment (in days)	Number of referrals in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		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