

Women's and Children
Metabolic Disorders
Lysosomal Storage Disorders (LSD) All Ages

E06/S(HSS)/c

Code	Metric	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Notes	Q1	Q2	Q3	Q4
E06/S(HSS)/c-22-108	Mean length of time from decision to treat to commencement of a disease modifying therapy (Enzyme Replacement Therapy (ERT), Substrate Reduction Therapy (SRT) and chaperone).	Mean length of time from decision to treat to treatment commencement of Disease Modifying Therapy (DMT)	Total patients who had treatment commenced in reporting period	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-109	Percentage of patients who died (excluding sudden unexpected deaths) in the reporting year who had been reviewed by the palliative care team in 24 months prior	Number of patients who died in the reporting year who had been reviewed by the palliative care team in 24 months prior	Patients who died during the reporting year which were not sudden and unexpected	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-110	Percentage of MPS and Fabry patients who undergo a cardiology assessment in the past 24 months	Number of MPS and Fabry patients who undergo a cardiology assessment (review by cardiologist or cardiology investigations) in the past 24 months	Total service caseload of MPS and Fabry patients	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-111	Fabry & MPS - Percentage of patients who suffer sudden cardiac death among patients treated for 3 years or more	Number of patients who suffer sudden cardiac death	Patients who have been on treatment for 3 years or longer	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-112	Gaucher 1 - Percentage of patients with a persistently low platelet count (<100 over 2 consecutive tests within a 12-month period) where their baseline level was above 100, treated for 3 years or more	Number of patients with a persistently low platelet count	Patients with a baseline platelet count above 100 who have been on treatment for 3 years or longer.	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-113	The proportion of patients who died in the reporting year who had an advanced care plan in place.	Patients who died with an advanced care plan	Patients who died over the course of the reporting year.	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-114	The proportion of patients and their families who are "satisfied" or "very satisfied" with the experience as reported in Q30 of the LSD Collaborative patient survey	Patients and families who are satisfied with the service	Patients and families who responded to the survey in the reporting year	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-115	The proportion of patients with MPS III with a documented swallow safety assessment with the Speech and Language team in the last 24 months.	Patients with a documented swallow safety assessment with the Speech and Language team in the last 24 months (local or specialist team).	Active caseload of MPS III patients	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-116	Proportion of patients with MPS II on active treatment (ERT or previous BMT) showing a post treatment reduction/stability of their uGAG/creatinine ratio	patients with MPS II on active treatment showing a post treatment reduction/stability of their uGAG/creatinine ratio	Active caseload of patients with MPS II on active treatment (who are not on a clinical trial)	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-117	Proportion of young adult LSD patients (14-17y) who are on the formal transition pathway	Number of LSD patients aged 14-17 years who are on the formal transition pathway	Active caseload of LSD patients aged 14-17 years	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23
E06/S(HSS)/c-22-118	Number of patients with MPS I/II/IVa/VI having an acute unexpected cervical spine pathology which requires urgent surgical intervention	Number of patients with MPS I/II/IVa/VI having an acute unexpected cervical spine pathology which requires urgent surgical intervention	Active caseload of patients with MPS I/II/IVa/VI	Annual	Annual	Provider	Provider			N/A	N/A	N/A	Apr 22 - Mar 23