

Women and Children
Metabolic disorders (E06)
Metabolic Disorders (Children)

E06/S/b

Code	Metric	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Construction	Q1	Q2	Q3	Q4
IMD01a-P	Proportion of newly identified MCADD NBS patients seen for a 'face-to-face review' by a designated clinical team within 24 hours of receiving the screening report and provided with necessary information and emergency regimen	The number of newly identified MCADD NBS patients seen for a 'faceto-face review ' by a designated clinical team within 24 hours of receiving the screening report and provided with necessary information and emergency regimen	Total number of new positive NBS diagnoses of MCADD at the centre	1 year	Annual	Provider Submitted	Provider submitted	90% or higher					Apr 22 - Mar 23
IMD02a-P	Proportion of patients with PKU identified by NBS, seen by the IMD team and started on dietary treatment by day 14 of life	The number of patients with PKU identified by NBS, seen by the IMD team and started on dietary treatment by day 14 of life	Total number of new diagnosis of PKU by NBS	1 year	Annual	Provider Submitted	Provider submitted	90% or higher					Apr 22 - Mar 23
IMD03-L-P	Proportion of newborn babies with a positive metabolic NBS result for PKU, IVA, GA1, MCADD and MSUD, seen by day 14 of life in a designated clinic	Number of new born babies with a positive metabolic NBS result for PKU, IVA, GA1, MCADD and MSUD, seen by day 14 of life in a designated clinic	Total number of new born babies with a positive metabolic NBS result for PKU, IVA, GA1, MCADD and MSUD	1 year	Annual	Provider Submitted	Provider submitted		1				Apr 22 - Mar 23
IMD04-L-P	Proportion of patients (adult and paediatric) with PKU whose Phe monitoring blood test results are reported within 3 working days of receipt by the laboratory	Number of patients with PKU whose Phe monitoring blood test results are reported within 3 working days of receipt by the laboratory (adult and paediatric)	Total number of Phe results reported during the year (adult and paediatric)	1 year	Annual	Provider Submitted	Provider submitted	90% or higher	Data for both adult and paediatric patients should be reported on for this indicator. This indicator will be reported on in both the Adult and Paediatric dashboards.				Apr 22 - Mar 23
IMD05a-L-P	Proportion of newborns with a positive screening test in whom confirmatory tests were completed within 5 working days of receipt of the diagnostic samples into the laboratory	Number of newborns with a positive screening test in whom confirmatory tests were completed within 5 working days of receipt of the diagnostic samples into the laboratory	Number of newborns with a positive metabolic NBS diagnostic test result	1 year	Annual	Provider Submitted	Provider submitted		1				Apr 22 - Mar 23
IMD06-L-P	CPA (UKAS) accreditation of the laboratory	Yes or No		3 years	Annual	Provider Submitted	Provider submitted		This indicator is reported on, in both the Adult and Paediatric dashboards.				Apr 22 - Mar 23
IMD07c-P	Completion of transition of care to an adult IMD team. Number of patients who are still under the care of the paediatric service after their 18th birthday.	Number of patients who are still under the care of the paediatric service after their 18th birthday		1 year	Annual	Provider Submitted	Provider submitted						Apr 22 - Mar 23
IMD09a-P	Percentage of positive friend and family test responses	From the denominator, the number of positive responses	The total number of friends and family responses	1 year	Annual	Provider Submitted	Provider submitted		Use friends and family results from outpatient clinics only. It is recognised that wording may vary trust by trust. A positive result is defined as one of the top two positive indicators e.g. 1. Highly likely or strongly agree or 2. Likely or agree.				Apr 22 - Mar 23

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IMD10b-P	Proportion of patients with propionic acidaemia (PA) and methylmalonic aciduria (MMA)(non-Vit B12 responsive) provided with an emergency regimen	Number of patients with PA and MMA (non-Vit B12 responsive) provided with an appropriate emergency regimen	Number of patients with PA and MMA (non-Vit B12 responsive) PA and MMA (non-Vit B12 responsive) provided with an appropriate emergency regimen	1 year	Annual	Provider Submitted	Provider submitted						Apr 22 - Mar 23
IMD11-P	Mortality and morbidity MDT meetings (At least 3 MDT M&M meetings per year should be held, with the minutes and outcomes documented) - Yes/No	Yes or No		Annual	Annual	Provider Submitted	Provider submitted						Apr 22 - Mar 23