

Inherited Metabolic Disorders (Paediatric) Quality Dashboard 2018/19

Indicator Reference Number	Domain	Theme	Measure	Rationale	Name of Indicator/Description	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Interpretation Guidance	Notes	Reporting Periods				
															Q1	Q2	Q3	Q4	
IMD01a-P	Domain 1 - Preventing people from dying prematurely	Clinical process measure	Timely first 'face-to-face' clinical review - newborns with a positive NBS result for MCADD	Patients with MCADD identified by Newborn Screening (NBS) should be seen by a designated clinical team for a 'face-to-face review' within 24 hrs of receiving the screening report from the laboratory and provided with necessary information and emergency regimen (MCADD NBS guidelines).	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 '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	Total number of new positive NBS diagnoses of MCADD at the centre	Annual	Annual	Provider submitted data	Provider submitted data	90% or higher	Higher is better					Apr 18 - Mar 19	
IMD02a-P	Domain 2 - Enhancing quality of life for people with long term conditions	Clinical process measure	Timely initiation of dietary treatment in newborns with PKU identified by NBS	Patients with PKU identified by NBS should be seen by the IMD team and started on dietary treatment by day 14 of life (NSPKU guidelines).	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	Annual	Annual	Provider submitted data	Provider submitted data	90% or higher	Higher is better					Apr 18 - Mar 19	
IMD03-L-P	Domain 1 - Preventing people from dying prematurely	Paediatric laboratory process measure	Timely clinical review - newborn babies with a positive metabolic NBS result for PKU, IVA, GA1, MCADD and MSUD	A newborn baby with a positive metabolic NBS result (PKU, MCAD, GA1, MSUD, IVA) should be seen by day 14 of life in a designated clinic.	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	Annual	Annual	Provider submitted data	Provider submitted data	100%	Higher is better					Apr 18 - Mar 19	
IMD04-L-P	Domain 2 - Enhancing quality of life for people with long term conditions	Laboratory process measure	Timely reporting of Phe monitoring blood test results	Phenylalanine (Phe) monitoring blood test results in patients with PKU, should be reported within 3 working days of receipt in the laboratory. It has been agreed by the CRG that this laboratory indicator should include data for both adult and paediatric patients.	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)	Annual	Annual	Provider submitted data	Provider submitted data	90% or higher	Higher is better	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 18 - Mar 19
IMD05a-L-P	Domain 3 - Ensuring that people have a positive experience of care	Paediatric laboratory process measure	Confirmatory testing following positive metabolic NBS tests	All positive metabolic NBS tests (PKU, MCAD, GA1, MSUD, HCU, IVA) should be followed by a confirmatory test within 5 working days of receipt of the diagnostic samples into the laboratory.	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	Annual	Annual	Provider submitted data	Provider submitted data	100%	Higher is better					Apr 18 - Mar 19	
IMD06-L-P	Domain 5 - Treating and caring for people in a safe environment and protect them from avoidable harm	Laboratory process measure	CPA (UKAS) accreditation of the laboratory	CPA accreditation (UKAS) is a mandatory requirement of all IMD and screening laboratories.	CPA (UKAS) accreditation of the laboratory	Yes or No	N/A	3 yearly	Annual	Provider submitted data	Provider submitted data			This indicator is reported on, in both the Adult and Paediatric dashboards.					Apr 16 - Mar 19
IMD07c-P	Domain 2 - Enhancing quality of life for people with long term conditions	Process measure	Completion of transition of care to an adult IMD team	The care of all IMD patients should be transitioned/transferred to an appropriate adult IMD service by their 18th birthday.	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	N/A	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better					Apr 18 - Mar 19	

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IMD09a-P	Domain 3 - Ensuring that people have a positive experience of care	Process measure	Patient experience	Patient feedback using the Friends and Family test should be sought by clinical teams and higher patient satisfaction is likely to reflect quality and patient-centred care.	Percentage of positive friend and family test responses	From the denominator, the number of positive responses	The total number of friends and family responses	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	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 18 - Mar 19
IMD10b-P	Domain 4 - Helping people to recover from episodes of ill health or following injury	Clinical process measure	Provision of appropriate regimen	All patients with propionic acidaemia (PA) and methylmalonic aciduria (MMA)(non-Vit B12 responsive) should be provided with an emergency regimen as per the BIMDG guidelines (www.bimdg.org.uk).	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)	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 18 - Mar 19
IMD11-P	Domain 5 - Treating and caring for people in a safe environment and protect them from avoidable harm	Process measure	Mortality and morbidity MDT meetings	Regular mortality and morbidity MDT meetings should be mandatory for all clinical teams.	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 data	Provider submitted data							Apr 18 - Mar 19

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