

Inherited Metabolic Disorders (Adults) Quality Dashboard 2018/19

Indicator Reference Number	Domain	Theme	Measure	Rationale	Indicator Name/Description	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Interpretation Guidance	Notes	Reporting Periods			
															Q1	Q2	Q3	Q4
IMD04-L-A	Domain 2 - Enhancing quality of life for people with long term conditions	Laboratory process measure	Time to 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 is reported on in both the adult and paediatric dashboards.				Apr 18 - Mar 19
IMD06-L-A	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	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
IMD09a-A	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
IMD10-A	Domain 4 - Helping people to recover from episodes of ill health or following injury	Clinical process measure	Provision of appropriate emergency regimen	All patients with urea cycle defects should be provided with an emergency regimen as per the BIMDG guidelines (www.bimdg.org.uk).	Proportion of patients with urea cycle defects provided with an emergency regimen	Number of patients with urea cycle defects with an appropriate emergency regimen	Number of patients with urea cycle defects	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 18 - Mar 19
IMD10b-A	Domain 4 - Helping people to recover from episodes of ill health or following injury	Clinical process measure	Provision of appropriate emergency 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) 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-A	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 held, with the minutes and outcomes documented	At least 3 MDT M&M meetings per year should be held, with the minutes and outcomes documented - (Yes or No)	N/A	Annual	Annual	Provider submitted data	Provider submitted data							Apr 18 - Mar 19
IMD12-A	Domain 5 - Treating and caring for people in a safe environment and protect them from avoidable harm	Clinical process measure	Dietary management of PKU in unplanned pregnancy / in cases where PKU treatment was not initiated before conception	In all mothers with PKU, the pregnancy should be planned, Plasma Phe concentration strictly maintained before and around the time of the conception and during the entire pregnancy, as per the NSPKU guidelines. In the unfortunate event of a pregnancy arising in a patient in whom Phe concentrations are not tightly controlled, dietary management should be initiated as soon as possible, after the patient informs the team about a positive pregnancy test.	Dietary management of PKU in unplanned pregnancy in cases where PKU treatment was not initiated before conception. The longest duration (in working days) between the time that IMD team was informed regarding a positive pregnancy and initiation of PKU treatment	The longest duration, in number of working days between the time that IMD team was informed regarding a positive pregnancy and initiation of PKU treatment in an unplanned pregnancy at the centre	N/A	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better	If there was more than one unplanned PKU pregnancy, provide the data for the longest delay in initiating PKU treatment within the indicator notes/comments.				Apr 18 - Mar 19

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