

Inherited Metabolic Disorders Quality Dashboard

Measure Number	Domain	Service Area	Description & Provenance	Name of KPI	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Data presentation	Target	Interpretation Guidance	Construction	Data Quality Concerns	Error Measurement	Notes_1
IMD01	1. Preventing people from dying prematurely	Paediatric	Patients with MCADD identified on NBS, seen by IMD team within 24 hrs of receiving the screening report from the lab and provided with necessary information and emergency regimen	Patients with MCADD identified on NBS, seen by IMD team within 24 hrs of receiving the screening report from the lab and provided with necessary information and emergency regimen	Newly identified MCADD NBS patients seen within 24 hours of receiving the screening report and provided with necessary information and emergency regimen	Total number of new diagnosis of MCADD by NBS at the centre	Annual		- From Trust /Collected by the IMD team	- From Trust /Collected by the IMD team		90% or higher					
IMD02	2. Enhancing quality of life for people with long term conditions	Paediatric	Patients with PKU identified on NBS, seen by IMD team and started on dietary treatment by day 14 of life (NSPKU guidelines)	Patients with PKU identified on NBS, seen by IMD team and started on dietary treatment by day 14 of life (NSPKU guidelines)	Patients with PKU identified on NBS, seen by IMD team and started on dietary treatment by day 14 of life	Total number of new diagnosis of PKU by NBS	Annual		- From Trust /Collected by the IMD team	- From Trust /Collected by the IMD team		90% or higher					
IMD03	1. Preventing people from dying prematurely	Laboratory	Time to first clinical visit following in a newborn baby with a positive newborn screening test	Time to first clinical visit following in a newborn baby with a positive newborn screening test	Number of children with a positive NBS result , seen within 14 days of age seen in a designated clinic	Total number of children with a positive NBS result	Annual		NBS Labs	NBS Labs		100%					
IMD04	2. Enhancing quality of life for people with long term conditions	Laboratory	Number of patients with PKU whose Phe monitoring blood test results are reported within 3 working days	Number of patients with PKU whose Phe monitoring blood test results are reported within 3 working days	Number of patients with PKU whose Phe monitoring blood test results are reported within 3 working days	Total number of Phe results reported during the year	Annual		- Audit/ from Trust /Collected by the IMD team	- Audit/ from Trust /Collected by the IMD team		90% or higher					
IMD05	3. Ensuring that people have a positive experience of care	Laboratory	Percentage of positive NBS tests that were followed by a confirmatory test within 7 working days	Percentage of positive NBS tests that were followed by a confirmatory test within 7 working days	Number of newborns with a positive screening test in whom the confirmatory tests were	Number of newborns with a positive screening test in whom the confirmatory tests were	Annual		- Audit/ from Trust /Collected by the IMD team	- Audit/ from Trust /Collected by the IMD team		100%					
IMD06	5.Treating and caring for people in a safe environment and protect them from avoidable harm	Laboratory	CPA accreditation is a requirement of all IMD and screening laboratories	CPA accreditation is a requirement of all IMD and screening laboratories	Yes/No		3 yearly		Local data	Local data							
IMD07	2. Enhancing quality of life for people with long term conditions	Paediatric Adult Laboratory	Number of patients over 18 years of age, who have completed the transition process to an adult IMD team (except for those for whom there is a specific indication for continuing care by the paediatric team)	Proportion of adults (>16 years) who continue to be managed in paediatric IMD centre	Number of patients over 18 years of age, who have completed the transition process to an adult IMD team successfully (except for those for whom there is a specific indication for continuing care by the paediatric team)	Total number of patients who are 18 years or older	Annual		- From Trust /Collected by the IMD team	- From Trust /Collected by the IMD team		the higher the better					Exemptions for those whose care has been continued in the paediatric centre for specific reasons such as learning difficulties etc
IMD08	2. Enhancing quality of life for people with long term conditions	Paediatric Adult Clinical	Number of adults /children with life-limiting conditions requiring palliative care, for whom there is a documented 'end of life' plan* or explicit agreement between the clinical team and the carers/family regarding management around the end of life	Number of adults /children with life-limiting conditions requiring palliative care, for whom there is a documented 'end of life' plan* or explicit agreement between the clinical team and the carers/family regarding management around the end of life	Number of adults /children with life-limiting conditions requiring palliative care, for whom there is a documented 'end of life' plan* or explicit agreement between the clinical team and the carers/family regarding management around the end of life	Total number of patients who are considered to have a life limiting condition and in 'palliative' care (not receiving active treatment).	Annual		- Audit/ from Trust /Collected by the IMD team	- Audit/ from Trust /Collected by the IMD team		the higher the better					to include Advance Care Plan and Do Not Resuscitate
IMD09	3. Ensuring that people have a positive experience of care	Paediatric Adult Clinical	Proportion / Percentage of positive feedback	Proportion / Percentage of positive feedback	Number of positive feedback received from patients/ families	Total number of patients/ families from whom feedback was requested	Annual		- Audit/ from Trust /Collected by the IMD team	- Audit/ from Trust /Collected by the IMD team		the higher the better					
IMD10	4.Helping people to recover from episodes of ill health or following injury	Paediatric Adult Clinical	Proportion of IMD patients with conditions that would require an emergency regimen (as detailed in the BIMDG guidelines, www.bimdg.org.uk),who have been provided with an updated version of one.	Proportion of IMD patients with conditions that would require an emergency regimen (as detailed in the BIMDG guidelines, www.bimdg.org.uk),who have been provided with an updated version of one.	Number of patients with an updated emergency regime	Number of IMD patients with conditions that would require an emergency regimen (as per BIMDG guidelines).	Annual		- Audit/ from Trust /Collected by the IMD team	- Audit/ from Trust /Collected by the IMD team		the higher the better					
IMD11	5.Treating and caring for people in a safe environment and protect them from avoidable harm	Paediatric Adult Clinical	Regular mortality and morbidity MDT meetings should be mandatory	At least 3 MDT M&M meetings should be held with the minutes and outcomes documented	Yes/No		3 yearly		Local data	Local data							
IMD12	5.Treating and caring for people in a safe environment and protect them from avoidable harm	Clinical Adult	In all mothers with PKU, the pregnancy should be planned, the diet should be strictly followed before and around the time of conception and during the entire pregnancy according to the NSPKU guidelines.	In all mothers with PKU, the pregnancy should be planned, the diet should be strictly followed before and around the time of conception and during the entire pregnancy according to the NSPKU guidelines.	Number of mothers with PKU in whom the pregnancy was planned, the PKU diet was initiated before conception and maintained during pregnancy	Total number of maternal PKUs	Annual		- Audit/ from Trust /Collected by the IMD team	- Audit/ from Trust /Collected by the IMD team		90% or higher					