

Specialised Services for Haemoglobinopathy (All Ages) Quality Dashboard 2019/20



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
HAEM02	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Trans Cranial Doppler (TCD) monitoring	TCD being delivered to at risk group plus assurance that national guidelines on frequency, methodology and training are being followed.	Proportion of children (aged between 2 and 16 years old) within at risk group (S/S and S/bets 0 Thal) receiving trans cranial doppler monitoring within Trust	Number of children having TCD monitoring within national guidelines	Total number who are eligible for TCD monitoring	6 month rolling	Quarterly	Provider submitted data	Provider submitted data		Higher is better		Jan 19 - Jun 19	Apr 19 - Sep 19	Jul 19 - Dec 19	Oct 19 - Mar 20
HAEM03i	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Timeliness of pain relief in sickle cell disease	Indicator to measure that patients are given pain relief within half an hour of presentation with sickle crisis, as per NICE guidelines.	Percentage of patients given pain relief within half an hour of presentation with sickle crisis, as per NICE guidelines	Number of patients achieving this standard	Total number of events (patients presenting with sickle crisis), within the reporting period.	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Annual reporting. If a specialist centre is supervising other Trusts then a minimum of an audit from those centres of this annually. This should only relate to pain relief given as an urgency with either within Emergency department or acute admissions unit.				Apr 19 - Mar 20
HAEM04A	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Screening to access to specialist care	Indicator to measure that all patients with possible sickle disorders identified by neonatal screening have entered care pathway.	Proportion of patients with possible sickle disorders identified by neonatal screening who have been entered onto care pathway	Number of patients entered onto care pathway	Total number of identified patients, within reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 19 - Mar 20
HAEM04B	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Screening to access to specialist care.	Indicator to measure the number of children beginning penicillin at or before 3 months of age, as per screening programme guidelines.	Percentage of eligible children beginning penicillin at or before 3 months of age as per screening programme guidelines	Number of children beginning penicillin within screening guidelines	Total number of children eligible to begin penicillin within reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 19 - Mar 20
HAEM05	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Annual review via NHR.	To measure data entry each year into annual review system of NHR.	Data entry each year into annual review system of NHR	Number of annual reviews undertaken by the centre as recorded by NHR entry within that year	Total number of registered patients eligible for annual reviews on NHR by that centre	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 19 - Mar 20
HAEM06Ai	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation, aimed predominantly at thassaemia, if any high risk sickle included please identify in return	Assessment of adequacy of chelation; Access to cardiac MRI.	Proportion of eligible patients on long term transfusion who receive cardiac MRI	Number of eligible patients (adults and children) on long term transfusion patients who receive cardiac MRI	Number of patients (adults and children) eligible for cardiac MRI, within the reporting period	Annual	Annual	Provider submitted data	Provider submitted data			If any high risk Sickle included, please note in the indicator comments/notes.				Apr 19 - Mar 20
HAEM06Aii	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation, aimed predominantly at thassaemia, if any high risk sickle included please identify in return	Measures adequacy of chelation; Cardiac MRI of more than 20 ms.	Proportion of patients receiving cardiac MRI who achieved more than 20 ms	Number of those who had MRI who achieved figure more than 20 ms	Number of patients who received cardiac MRI within reporting period	Annual	Annual	Provider submitted data	Provider submitted data			If any high risk Sickle included, please note in the indicator comments/notes.				Apr 19 - Mar 20
HAEM06Bi	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation, sickle only	Measures adequacy of chelation; MRI assessment of liver iron less than 7 mg/gm/DW liver tissue using Ferriscan, if using T2* then less than 4 mg/gm /DW.	Proportion of eligible patients who receive MRI for liver iron - sickle only	Number of eligible patients who receive MRI for liver iron - sickle only	Total number of transfused/chelated patients supervised by centre eligible to have MRI for liver iron within reporting period - sickle only	Annual	Annual	Provider submitted data	Provider submitted data			Provider organisations to add note in the indicator comments as to the MRI technology in use (i.e. T2* or R2).				Apr 19 - Mar 20
HAEM06Bii	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Assessment of adequacy of chelation, sickle only	Measure adequacy of chelation; MRI assessment of liver iron less than 7 mg/gm/DW liver tissue using Ferriscan, if using T2* then less than 4 mg/gm /DW.	Proportion of patients receiving MRI for liver iron who achieved less than 7 mg/gm/DW liver iron - sickle only	Number of those who had MRI who achieved less than 7 mg/gm/DW liver iron - sickle only	Number of patients who received MRI for liver iron within reporting period - sickle only	Annual	Annual	Provider submitted data	Provider submitted data			Provider organisations to add note in the indicator comments as to the MRI technology in use (i.e. T2* or R2). If using T2* then less than 4 mg/gm /DW, please state MRI technology in use at centre i.e. T2* or R2.				Apr 19 - Mar 20

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HAEM06Ci	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation, Thalassaemia only	Measure adequacy of chelation; MRI assessment of liver iron less than 7 mg/gm/DW liver tissue using Ferriscan, if using T2* then less than 4 mg/gm /DW.	Proportion of eligible patients who receive MRI for liver iron - thalassaemia only	Number of eligible patients who receive MRI for liver iron - thalassaemia only	Total number of transfused/chelated patients supervised by centre eligible to have MRI for liver iron within the reporting period - thalassaemia only	Annual	Annual	Provider submitted data	Provider submitted data			Provider organisations to add note in the indicator comments as to the MRI technology in use (i.e. T2* or R2).				Apr 19 - Mar 20
HAEM06Cii	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Assessment of adequacy of chelation, Thalassaemia only	Measures adequacy of chelation; MRI assessment of liver iron less than 7 mg/gm/DW liver tissue using Ferriscan, if using T2* then less than 4 mg/gm /DW.	Proportion of patients receiving MRI for liver iron who achieved less than 7 mg/gm/DW liver iron - thalassaemia only	Number of those who had MRI who achieved less than 7 mg/gm/DW liver iron - thalassaemia only	Number of patients who received MRI for liver iron within the reporting period - thalassaemia only	Annual	Annual	Provider submitted data	Provider submitted data			Provider organisations to add note in the indicator comments as to the MRI technology in use (i.e. T2* or R2). If using T2* then less than 4 mg/gm /DW, please state MRI technology in use at centre i.e. T2* or R2.				Apr 19 - Mar 20

Data collection has been approved by the Review of Central Returns - ROCR
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