

### Haemoglobinopathy Quality Dashboard

Ref	Domain	Measure	Measurement definition	KPI	Numerator	Denominator	How much data should be aggregated	Frequency	Data collection	Data presentation	Notes 1	Notes 2
HAEM01	Domain 3: Helping people to recover from episodes of ill health or following injury	Serious events entered on to NHR system and reviewed within network morbidity/mortality meetings	Evidence that each adverse event has been reviewed within network by either mortality review or serious case review . Input to national review of all adverse events.	Proportion of serious events entered on to NHR system and reviewed within network morbidity/mortality meetings	Number of adverse events reported that have been reviews within the network by either mortality or serious case review	Total number of adverse events reported on NHR within reporting period	Six months	Six monthly	From all Trusts Local and Specialist	simple %? and variation between centres/networks		
HAEM02	Domain 3: Helping people to recover from episodes of ill health or following injury	Number of children (aged between 2 and 16 years old) within at risk group ( S/5 and S/bets 0 Thal ) receiving Trans cranial Doppler monitoring within network.	TCD being delivered to at risk group plus assurance that national guidelines on frequency,methodology and training being followed .	Proportion of children (aged between 2 and 16 years old) within at risk group ( S/5 and S/bets 0 Thal ) receiving Trans cranial Doppler monitoring within network.	Number of children having TCD monitoring within national guidelines.	Total number who are eligible for TCD monitoring.	Six months	Six monthly	From Specialist Trust only	simple %? Plus assessed as variation across networks		
HAEM03	Domain 3: Helping people to recover from episodes of ill health or following injury	Timeliness of pain relief in Sickle Cell Disease.	% of patients 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 reporting period	Six months	Six monthly	From all Trusts Local and Specialist	Simple percentage assessed both by variation between Trusts and by network	We would initially accept to an audit rather than the total per year . If a specialist centre is supervising other Trusts then we would expect 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 .
HAEM04A	Domain 3: Helping people to recover from episodes of ill health or following injury	Screening to access to specialist care.	All patients with possible Sickle disorders identified by neonatal screening have entered care pathway	Proportion of patients identified by neonatal screening who have entered onto care pathway	Number of patients entered onto care pathway	Total number of identified patients within reporting period	12 monthly	Annually	From Specialist Trust only	presented as variation between networks		
HAEM04B	Domain 3: Helping people to recover from episodes of ill health or following injury	Screening to access to specialist care	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	12 monthly	Annually	From Specialist Trust only	presented as variation between networks		
HAEM05	Domain 3: Helping people to recover from episodes of ill health or following injury	Adequate annual review via NHR	Adequate data entry each year into annual review system of NHR	Adequate 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	12 months	Annually	By all Trusts using annual review system of NHR	presented by Trust and network variation		
HAEM06Ai	Domain 2 number of patients on long term transfusion	Assessment of adequacy of chelation, aimed predominantly at Thassaemia , if any high risk Sickle included please identify in return	Access to cardiac MRI	Proportion of eligible patients 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 reporting period	12 monthly	Annually	From Specialist Trust only	presented by Trust and network variation	if any high risk Sickle included please identify in return	
HAEM06Aii	Domain 2 number of patients on long term transfusion	Assessment of adequacy of chelation, aimed predominantly at Thassaemia , if any high risk Sickle included please identify in return	Measure 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 MIR within reporting period	12 monthly	Annually	From Specialist Trust only	presented by Trust and network variation	if any high risk Sickle included please identify in return	
HAEM06Bi	Domain 2 number of patients on long term transfusion	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, please state MRI technology in use at centre ie T2* or R2	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	12 monthly	Annually	From Specialist Trust only	Presented by Trust and network variation	Please note in comments section of submission template the MRI technology in use (ie T2* or R2)	
HAEM06Bii	Domain 2 number of patients on long term transfusion	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, please state MRI technology in use at centre ie T2* or R2	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	12 monthly	Annually	From Specialist Trust only	Presented by Trust and network variation	Please note in comments section of submission template the MRI technology in use (ie T2* or R2)	if using T2* then less than 4 mg/gm /DW, please state MRI technology in use at centre ie T2* or R2
HAEM06Ci	Domain 2 number of patients on long term transfusion	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, please state MRI technology in use at centre ie T2* or R2	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 reporting period - THALASSAEMIA only	12 monthly	Annually	From Specialist Trust only	Presented by Trust and network variation	Please note in comments section of submission template the MRI technology in use (ie T2* or R2)	

HAEM06Cii	Domain 2 number of patients on long term transfusion	Assessment of adequacy of chelation , Thalassemia 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, please state MRI technology in use at centre ie T2* or R2	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	Numbr of patients who received MRI for liver iron within reporting period - THALASSAEMIA only	12 monthly	Annually	From Specialist Trust only	Presented by Trust and network variation	Please note in comments section of submission template the MRI technology in use (ie T2* or R2)	if using T2* then less than 4 mg/gm /DW, please state MRI technology in use at centre ie T2* or R2
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