

Specialised Services for Specialist Haemoglobinopathy Teams (SHT) (All Ages) Quality Dashboard 2020/21

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 and assurance that national guidelines on frequency, methodology and training are being followed.	Proportion of paediatric patients (aged between 2 and 16 years old) within at risk group (HbSS, HbS/Beta zero Thalassaemia) undergoing TCD monitoring.	Of those in the denominator, the number of paediatric patients undergoing TCD monitoring within national guidelines	The total number of paediatric patients who are eligible for TCD monitoring in the reporting period	6 month rolling	Quarterly	Provider submitted data	Provider submitted data		Higher is better		Jan 20 - Jun 20	Apr 20 - Sep 20	Jul 20 - Dec 20	Oct 20 - Mar 21
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 30 minutes of presentation with a sickle cell crisis, as per NICE guidelines.	Percentage of patients given pain relief within 30 minutes of presentation with a sickle cell crisis, as per NICE guidelines.	Of those in the denominator, the number of patients that receive pain relief within 30 minutes of presentation with a sickle cell crisis	The total number of events (patients presenting with sickle cell crisis) in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Annual reporting. If an SHT is supervising other Trusts, then a minimum of an audit from that SHT annually. This should only relate to pain relief given urgently, either within an emergency department or acute admissions unit. Include all patients - adults and paediatrics.	N/A	N/A	N/A	Apr 20 - Mar 21
HAEM04A	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Screening to specialist care access	Indicator to measure, that all paediatric patients with possible sickle cell disease identified by neonatal screening, have entered the care pathway.	Proportion of paediatric patients with possible sickle cell disease identified by neonatal screening, who have been entered into the care pathway.	Of those in the denominator, the number of paediatric patients entered into the care pathway	The total number of paediatric patients with possible sickle cell disease, identified by neonatal screening in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
HAEM04Bi	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 paediatric patients beginning antibiotics at or before 3 months of age, as per screening programme guidelines.	Proportion of eligible paediatric patients beginning antibiotics at or before 3 months of age, as per screening programme guidelines	Of those in the denominator, the number of paediatric patients beginning antibiotics at or before 3 months of age as per screening programme guidelines	The total number of paediatric patients eligible to begin antibiotics in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
HAEM05	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Annual review via the NHR.	To measure data entry each year into annual review system of the NHR.	Proportion of annual reviews recorded by the NHR.	Of those in the denominator, the number of annual reviews undertaken by the centre as recorded by NHR entry.	The total number of registered patients eligible for annual reviews via the NHR by that centre in the reporting period.	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Include all patients - adults and paediatrics				Apr 20 - Mar 21
HAEM06Ai	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation, aimed predominantly at Thalassaemia.	Assessment of adequacy of chelation; access to cardiac T2* MRI.	Proportion of eligible patients on long term transfusions who undergo cardiac T2* MRI.	Of those in the denominator, the number of eligible patients on long term transfusions, who undergo cardiac T2* MRI.	The total number of patients eligible for cardiac T2* MRI in the reporting period.	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Eligibility defined by: 1. Most recent T2* Cardiac MRI < 20ms 2. Most recent Ferriscan with LIC > 15 mg Iron / gm dry weight. Include all patients - adults and paediatrics				Apr 20 - Mar 21
HAEM07	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of utilisation of Hydroxycarbamide in paediatric patients with sickle cell disease	Indicator to measure the proportion of paediatric patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia) on Hydroxycarbamide	Proportion of eligible paediatric patients (> 9 months of age) who are offered, or currently on Hydroxycarbamide	Of those in the denominator, the total number of paediatric patients currently offered or currently on Hydroxycarbamide	The total number of paediatric patients eligible to receive Hydroxycarbamide in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
HAEM08	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of utilisation of Hydroxycarbamide in adults with sickle cell disease.	Indicator to measure the proportion of adults with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia) on Hydroxycarbamide	Proportion of eligible adults who are offered or currently on Hydroxycarbamide	Of those in the denominator, the total number of adults currently offered, or currently on Hydroxycarbamide	The total number of adults eligible to receive Hydroxycarbamide in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
HAEM09a	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of modality of regular transfusion programmes in patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia).	Indicator to measure the proportion of regularly transfused patients with sickle cell disease (HbSS, HbSC, HbS / Beta Thalassaemia) by transfusion modality	Proportion of regularly transfused paediatric patients on simple top-up transfusions	Total number of paediatric patients on regular transfusions undertaken by simple top-up transfusions	The total number of paediatric patients on regular transfusions in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
HAEM09b	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of modality of regular transfusion programmes in patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia).	Indicator to measure the proportion of regularly transfused patients with sickle cell disease (HbSS, HbSC, HbS / Beta Thalassaemia) by transfusion modality	Proportion of regularly transfused adult patients on simple top-up transfusions	Total number of adult patients on regular transfusions undertaken by simple top-up transfusions	The total number of adult patients on regular transfusions in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
HAEM10a	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of modality of regular transfusion programmes in patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia).	Indicator to measure the proportion of regularly transfused patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia) by transfusion modality	Proportion of regularly transfused paediatric patients on manual exchange transfusions	Of those in the denominator, the number of paediatric patients on regular transfusions undertaken by manual exchange transfusions	The total number of paediatric patients on regular transfusions in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21

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HAEM10b	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of modality of regular transfusion programmes in patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia).	Indicator to measure the proportion of regularly transfused patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia) by transfusion modality	Proportion of regularly transfused adult patients on manual exchange transfusions	Of those in the denominator, the number of adult patients on regular transfusions undertaken by manual exchange transfusions	The total number of adult patients on regular transfusions in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better		N/A	N/A	N/A	Apr 20-Mar 21
HAEM11a	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of modality of regular transfusion programmes in patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia)	Indicator to measure the proportion of regularly transfused patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia) by transfusion modality	Proportion of regularly transfused paediatric patients on automated exchange transfusions	Of those in the denominator, the number of paediatric patients on regular transfusions undertaken by automated exchange transfusions	The total number of paediatric patients on regular transfusions in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20-Mar 21
HAEM11b	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of modality of regular transfusion programmes in patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia)	Indicator to measure the proportion of regularly transfused patients with sickle cell disease (HbSS, HbSC, HbS/Beta Thalassaemia) by transfusion modality	Proportion of regularly transfused adult patients on automated exchange transfusions.	Of those in the denominator, the number of adult patients on regular transfusions undertaken by automated exchange transfusions	The total number of adult patients on regular transfusions in the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better		N/A	N/A	N/A	Apr 20-Mar 21
Data collection has been approved by the Review of Central Returns - ROCR ROCR/CR/2230001MAND																		