# Haemoglobin Disorders Review Programme Background Report: *[Insert Name of your Centre/ Service Trust]*

This form provides the opportunity for Haemoglobinopathy Coordinating Centres (HCC) and Specialist Haemoglobinopathy Teams (SHT) to tell the reviewers about their service.

You will not need to complete a self-assessment. The information requested will also **provide compliance** for some of the Quality Standards so that reviewers do not need to see any further evidence on the visit day. Where this is the case the QS number is included. This will result in this report taking some time to complete, so please allow enough preparation time.

In addition, we will request to access some evidence before the visit which is included in the appendix to this document. Evidence should be made available via a SharePoint link where ever possible and we will discuss this with the leads when planning your visit.

**Instructions**

We are keen to minimise the duplication of information you need to send us so ***if you have the information in your annual report then please say so, send us your annual report and reference the page number where we can find the evidence in your annual report in the section below.***

Please complete this self-assessment questionnaire as fully as possible. If some questions are not applicable for your service, please state this rather than leaving blank.

The completed questionnaire should be sent to [mlcsu.nuct@nhs.net](mailto:mlcsu.nuct@nhs.net) not later than 3 weeks before the visit to support them to prepare and plan for your peer review visit. The sections are colour coded as follows:-

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|  | **Section 1: HCC Specific questions which can be completed jointly or separately for Adult and Childrens** |
|  | **Section 2: General questions for SHTs including information about linked LHTs** |
|  | **Section 3: Children and Young People SHT specific questions** |
|  | **Section 4: Adults SHT specific questions** |

**Non-attributability of data**

This data will be handled with the highest practical standards in accordance with the [8 Caldicott principles](https://www.gov.uk/government/publications/the-caldicott-principles) and [7 GDPR principles](https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/data-protection-principles/a-guide-to-the-data-protection-principles/#the_principles). The information you provide will be used in the context of the review and beyond that will be non-attributable to individuals part of the review. Please **do NOT** include patient identifiable data.

**Section 1: Haemoglobinopathy Coordinating Centres to complete in addition to the SHT sections**

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| **HEAMOGLOBINOPATHY COORDINATING CENTRES - Lead service to complete** | | | | |
| Name of SHTs within your HCC | | | A - Adults, C- Children, B - both | |
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| **QS**  **HA - 703**  **HA - 706**  **HA - 707** | **HCC Specific** | **Y/N** | **Comment** | |
| Has the HCC met with commissioners in the last year to: | | |  | |
| * Review progress on the previous year’s annual programme of work | |  |  | |
| * Review progress with improving patient experience and clinical outcomes across the network | |  |  | |
| * Agreed the annual programme of work for the forthcoming year | |  |  | |
| **HCC Audits - Please list** | | **Completed** | | **Active** |
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| **HCC Research agreed list of research trials available and those areas participating** | | **Completed** | | **Active** |
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| **INNOVATIONS TO SHARE** | | | | |
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| **AREAS FOR DEVELOPMENT/CHALLENGES OVER THE NEXT TWO TO THREE YEARS** | | | | |
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| **ANY OTHER RELEVANT BACKGROUND INFORMATION** | | | | |
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**Section 2: Specialist Haemoglobinopathy Teams – general information covering adults and children’s services**

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|  | | | **INTRODUCTION TO SERVICE(S)** | | | | | | | |
|  | |  | ***(Please include any general background information about the service/s which may be useful to reviewers)*** | | | | | | | |
|  | | | **CARE OF ADULTS** | | | | | | | |
| SHT | | |  | Hospital Site | |  | Linked Local Haemoglobinopathy Teams (LHT) | | | |
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|  | | | **CARE OF CHILDREN AND YOUNG PEOPLE** | | | | | | | |
| SHT | | |  | Hospital Site | |  | Linked Local Haemoglobinopathy Teams (LHT) | | | |
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|  | |  | **PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM** | | | | | | | |
| **Condition** | | **Total number of registered patients** | **No. active patients (those who have had hospital contact in the last 12 months)** | | **No. patients who have had an annual review in last year** | | | **No. patients on long-term transfusion** | **No. of eligible patients on hydroxycarbamide** | **No. in-patient admissions in last year** |
| Sickle Cell Disease | Adults |  |  | |  | | |  |  |  |
| Children |  |  | |  | | |  |  |  |
| Thalassaemia and rare inherited anaemias | Adults |  |  | |  | | |  |  |  |
| Children |  |  | |  | | |  |  |  |

| **PATHWAYS FOR EMERGENCY CARE** |
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| ***[Please add a short description including arrangements for direct ward admission, if available]*** |

| **FACILITIES AND ARRANGEMENTS FOR:** |
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| ***[Under each heading, please give a short summary of the size of the facility, activity levels (if available) and whether or not specific to patients with haemoglobin disorders]*** |
| **Ward Care:** |
| **Day unit Care:** |
| **Outpatient Care:** |
| **Community-based Care:** |

**SHT linked LHTs (Add or delete tables as required in this part of section 2)**

**LHT 1**

| **USUALLY SEEN BY THE LINKED HOSPITALS/LOCAL TEAMS (except for annual reviews)** | | | | | |  |  |
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| ***[Name of Trust/ Hospital]*** | | **Total number of registered patients** | **No. active patients (those who have had hospital contact in the last 12 months)** | **No. patients who have had an annual review in last year – if applicable** | **No. patients on long-term transfusion** | **No. of eligible patients on hydroxycarbamide** | **No. in-patient admissions in last year** |
| Sickle Cell Disease | Adults |  |  |  |  |  |  |
| Children |  |  |  |  |  |  |
| Thalassaemia and rare inherited anaemias | Adults |  |  |  |  |  |  |
| Children |  |  |  |  |  |  |
| **Other patients receiving red cell blood transfusions (please give details)** | | | | | |  |  |
| ***[Name of Trust/Hospital]*** | | **No. patients** | **Reason for transfusion** | **Reason for transfusion** | **Reason for transfusion** | | |
| Adults | |  |  |  |  | | |
| Children | |  |  |  |  | | |
| **ANY COMMENTS ON PATIENT NUMBERS** | | | | | |  |  |
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| **Local haemoglobinopathy team staffing – Name of Trust** | | |
| **Staffing for the Adult Local Haemoglobinopathy Service (LHT)** | **Number of patients** | **Actual WTE**  **(at time of visit)** |
| Consultant haematologist dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical nurse specialist dedicated to work with patients with adult patients with haemoglobinopathies? |  |  |
| Clinical psychologist dedicated to work with patients with adult patient with haemoglobinopathies? |  |  |
| **Staffing for the Children’s Local Haemoglobinopathy Service (LHT)** | **Number of patients** | **Actual WTE**  **(at time of visit)** |
| Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical nurse specialist for paediatric patients dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies? |  |  |

**LHT 2**

| **USUALLY SEEN BY THE LINKED HOSPITALS/LOCAL TEAMS (except for annual reviews)** | | | | | | | |
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| ***[Name of Trust/ Hospital]*** | | **Total number of registered patients** | **No. active patients (those who have had hospital contact in the last 12 months)** | **No. patients who have had an annual review in last year – if applicable** | **No. patients on long-term transfusion** | **No. of eligible patients on hydroxycarbamide** | **No. in-patient admissions in last year** |
| Sickle Cell Disease | Adults |  |  |  |  |  |  |
| Children |  |  |  |  |  |  |
| Thalassaemia and rare inherited anaemias | Adults |  |  |  |  |  |  |
| Children |  |  |  |  |  |  |
| **Other patients receiving red cell blood transfusions (please give details)** | | | | | |  |  |
| ***[Name of Trust/Hospital]*** | | **No. patients** | **Reason for transfusion** | **Reason for transfusion** | **Reason for transfusion** | | |
| Adults | |  |  |  |  | | |
| Children | |  |  |  |  | | |
| **ANY COMMENTS ON PATIENT NUMBERS** | | | | | |  |  |
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| **Local haemoglobinopathy team staffing – Name of Trust** | | |
| **Staffing for the Adult Local Haemoglobinopathy Service (LHT)** | **Number of patients** | **Actual WTE**  **(at time of visit)** |
| Consultant haematologist dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical nurse specialist dedicated to work with patients with adult patients with haemoglobinopathies? |  |  |
| Clinical psychologist dedicated to work with patients with adult patient with haemoglobinopathies? |  |  |
| **Staffing for the Children’s Local Haemoglobinopathy Service (LHT)** | **Number of patients** | **Actual WTE**  **(at time of visit)** |
| Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical nurse specialist for paediatric patients dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies? |  |  |

**LHT 3**

| **USUALLY SEEN BY THE LINKED HOSPITALS/LOCAL TEAMS (except for annual reviews)** | | | | | |  |  |
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| ***[Name of Trust/ Hospital]*** | | **Total number of registered patients** | **No. active patients (those who have had hospital contact in the last 12 months)** | **No. patients who have had an annual review in last year – if applicable** | **No. patients on long-term transfusion** | **No. of eligible patients on hydroxycarbamide** | **No. in-patient admissions in last year** |
| Sickle Cell Disease | Adults |  |  |  |  |  |  |
| Children |  |  |  |  |  |  |
| Thalassaemia and rare inherited anaemias | Adults |  |  |  |  |  |  |
| Children |  |  |  |  |  |  |
| **Other patients receiving red cell blood transfusions (please give details)** | | | | | |  |  |
| ***[Name of Trust/Hospital]*** | | **No. patients** | **Reason for transfusion** | **Reason for transfusion** | **Reason for transfusion** | | |
| Adults | |  |  |  |  | | |
| Children | |  |  |  |  | | |
| **ANY COMMENTS ON PATIENT NUMBERS** | | | | | |  |  |
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| **Local haemoglobinopathy team staffing – Name of Trust** | | |
| **Staffing for the Adult Local Haemoglobinopathy Service (LHT)** | **Number of patients** | **Actual WTE**  **(at time of visit)** |
| Consultant haematologist dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical nurse specialist dedicated to work with patients with adult patients with haemoglobinopathies? |  |  |
| Clinical psychologist dedicated to work with patients with adult patient with haemoglobinopathies? |  |  |
| **Staffing for the Children’s Local Haemoglobinopathy Service (LHT)** | **Number of patients** | **Actual WTE**  **(at time of visit)** |
| Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical nurse specialist for paediatric patients dedicated to work with patients with haemoglobinopathies? |  |  |
| Clinical psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies? |  |  |

**Section 3: Children and Young People Specialist Haemoglobinopathy Team**

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| **QS**  **HC - 197** | **GATHERING VIEWS OF CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES - RESULTS AND THEMES** | |
| Date of last survey(s) | | Sickle Cell |
| Thalassaemia |
| Number of responses received and analysed | | Sickle Cell |
| Thalassaemia |
| Results and themes (List) | | |
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| **QS**  **HC - 201**  **HC - 202**  **HC - 204 (part)** | **LEAD TEAM – Children and Young People**  **CYP HCC and /or Specialist Haemoglobinopathy Service (SHT) [[1]](#footnote-1)** | | | |
|  | **Name(s)** | **Number of PAs** | **Actual WTE (at time of the visit)** |
| 1. Lead Consultant SHT   UK Forum on Haemoglobin Disorders, recommends one Programmed Activity (PA) session per week for the clinical lead for a geographic area.   1. Lead Consultant HCC   HCC lead clinicians should have sufficient time for their network-wide role, including for service development and liaison with other services across the network. | |  |  |  |
| **Deputy for Lead Consultant** | |  | | |
| Lead Nurse | |  | N/A |  |

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| **QS**  **HC - 203**  **HC - 204**  **HC – 207**  **HC-208**  **HC-299** | **Staffing for the Children and Young People Specialist Haemoglobinopathy Service (SHT) [[2]](#footnote-2)** | **Number of patients** | **Actual WTE or PA**  **(at time of the visit)** |
| Consultant haematologist 1.5 PA for every 50 patients for direct clinical duties\* made up as:   * + - 1. Clinics including specialist annual review (2.0 hours/week)       2. Ward rounds (1.5 hours/week)       3. Day unit attendance and ad hoc consultations, on call (1.0 hour/week)       4. Clinical administration and MDT meetings (1.5 hours/week)   Additional PAs as required (e.g., for specialist training, laboratory work, research, outreach clinics)- reviewers will ask about this. | |  |  |
| At least 0.25 PA allocated to haemoglobinopathies CPD in the Adult Consultant Job plan. | |  |  |
| Trust employs a clinical nurse specialist(s) with responsibility to work with adult  patients with haemoglobinopathies for acute service and community service? | |  |  |
| Trust employ a clinical psychologist for adult patients who has >1 WTE per 300 patients dedicated to work with patients with haemoglobinopathies? | |  |  |
| There is administrative, clerical and data collection support appropriate for the number of patients cared for by the service. | | |  |

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| **QS**  **HC - 207**  **HC - 208**  **HC - 304** | **Nurse Staffing, Urgent Care Staff and Competences** | | **Y/N** | |
| A competence framework(s) in place covering: | | | | |
| * Nursing Staff | | |  | |
| * Psychology Staff | | |  | |
| * Medical and nursing staff working in Emergency Departments and admission units | | |  | |
| Are nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion? | | |  | |
| **Staffing** | | **Ward Name/number** | **Actual WTE (at time of the visit)** | **% vacancy rate** |
| The service has sufficient nursing staff with appropriate competence in the care of people with haemoglobin disorders | |  |  |  |
| Ward-based nursing staff (This covers nursing staff on wards to which people with haemoglobin disorders are usually admitted) | |  |  |  |
| Day unit (or equivalent) nursing staff | |  |  |  |

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| 1. QS 2. HC - 205 3. HC - 206 | Medical Staffing and Competences: Unscheduled Care and Doctors in Training | **Y/N** | **Comments** |
| SHTs and HCCs only: Is there 24/7 consultant and junior staffing for unscheduled care available? | |  |  |
| If doctors in training are part of achieving QSs HC-204 or HC-205 then do they have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders? | |  |  |

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| 1. QS 2. HC - 301 | Support Services | **Y/N** | **Comments** |
| * 1. Social worker / benefits adviser | |  |  |
| * 1. Play specialist / youth worker | |  |  |
| * 1. Dietetics | |  |  |
| * 1. Physiotherapy (inpatient and community-based) | |  |  |
| * 1. Occupational therapy | |  |  |
| * 1. Child and adolescent mental health services | |  |  |
| 1. QS 2. HC- 302 | Specialist Support - access to | **Y/N** | **Comments** |
| * 1. DNA studies | |  |  |
| * 1. Genetic counselling | |  |  |
| * 1. Sleep studies | |  |  |
| * 1. Diagnostic radiology | |  |  |
| * 1. Manual exchange transfusion (24/7) | |  |  |
| * 1. Automated red cell exchange transfusion (24/7) | |  |  |
| * 1. Pain team including specialist monitoring of patients with complex analgesia needs | |  |  |
| * 1. Level 2 and 3 critical care | |  |  |

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| **Guidelines and Protocols in place (these should also be made available /submitted prior to the review )** | | **Y/N** | **Review Date** |
| QS HC - 501 Transition Guidelines | |  |  |
| QS HC - 502 New Patient and Annual Review Guidelines | |  |  |
| QS HC - 503 Clinical Guidelines: LHT Management and Referral | |  |  |
| QS HC - 504 Transcranial Doppler Ultrasound Standard Operating Procedure | |  |  |
| QS HA - 505 Transfusion Guidelines | |  |  |
| QS HA - 506 Chelation Therapy | |  |  |
| QS HA - 507 Hydroxycarbamide and Other Disease Modifying Therapies | |  |  |
| QS HA - 508 Non-Transfusion Dependent Thalassaemia (nTDT) | |  |  |
| QS HA - 509 Clinical Guidelines: Acute Complications | |  |  |
| QS HA - 510 Clinical Guidelines: Chronic Complications | |  |  |
| QS HA - 511 Anaesthesia and Surgery | |  |  |
| 1. QS 2. HC - 705 | 1. SHT Audits | **Completed** | **Active** |
| The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) | |  |  |
| Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions | |  |  |
| 1. List participation in HCC agreed research trials | | **Completed** | **Active** |
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| **INNOVATIONS TO SHARE** |
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| **AREAS FOR DEVELOPMENT/CHALLENGES OVER THE NEXT TWO TO THREE YEARS** |
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| **ANY OTHER RELEVANT BACKGROUND INFORMATION** |
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**Completed by**

Name:

Date:

**Section 4: Adult Specialist Haemoglobinopathy Teams**

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| **QS**  **HA - 197** | **GATHERING VIEWS OF ADULTS - RESULTS AND THEMES** | |
| Date of last survey(s) | | Sickle Cell |
| Thalassaemia |
| Number of responses received and analysed | | Sickle Cell |
| Thalassaemia |
| Results and themes (List) | | |
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| **QS**  **HA - 201**  **HA - 202**  **HA - 204 (part)** | **LEAD TEAM – Adults**  **HCC and/or Specialist Haemoglobinopathy Service (SHT) [[3]](#footnote-3)** | | | |
|  | **Name(s)** | **Number of PAs** | **Actual WTE (at time of the visit)** |
| 1. Lead Consultant SHT   UK Forum on Haemoglobin Disorders, recommends one Programmed Activity (PA) session per week for the clinical lead for a geographic area.   1. Lead Consultant HCC   HCC lead clinicians should have sufficient time for their network-wide role, including for service development and liaison with other services across the network. | |  |  |  |
| **Deputy for Lead Consultant** | |  | | |
| Lead Nurse | |  | N/A |  |
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| **QS**  **HA - 203**  **HA - 204**  **HA - 207**  **HA - 209** | **Staffing for the Adult Specialist Haemoglobinopathy Service (SHT) [[4]](#footnote-4)** | | **Number of patients** | **Actual WTE or PA**  **(at time of the visit)** |
| Consultant haematologist 1.5 PA for every 50 patients for direct clinical duties\* made up as:   * + - 1. Clinics including specialist annual review (2.0 hours/week)       2. Ward rounds (1.5 hours/week)       3. Day unit attendance and ad hoc consultations, on call (1.0 hour/week)       4. Clinical administration and MDT meetings (1.5 hours/week)   Additional PAs as required (e.g., for specialist training, laboratory work, research, outreach clinics)- reviewers will ask about this | | |  |  |
| At least 0.25 PA allocated to haemoglobinopathies CPD in the Adult Consultant Job plan | | |  |  |
| Trust employ a clinical nurse specialist/s with responsibility to work with adult  patients with haemoglobinopathies for acute service and community service? | | |  |  |
| Trust employ a clinical psychologist for adult patients who has >1 WTE per 300 patients dedicated to work with patients with haemoglobinopathies? | | |  |  |
| There is administrative, clerical and data collection support appropriate for the number of patients cared for by the service. | | | |  |
| **QS**  **HA - 207 HA - 208**  **HA - 304** | **Nurse Staffing, Urgent Care Staff and Competences** | | **Y/N** | |
| A competence framework(s) in place covering | | | | |
| * Nursing Staff | | |  | |
| * Psychology Staff | | |  | |
| * Medical and nursing staff working in Emergency Departments and admission units | | |  | |
| Are nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion | | |  | |
| **Nurse Staffing -** The service should have sufficient nursing staff with appropriate competences in the care of adults with haemoglobin disorders, including: | | **Ward Name/number** | **Establishment (WTE)** | **% vacancy rate** |
| * 1. Clinical nurse specialist(s) with responsibility for the acute service   2. Clinical nurse specialist(s) with responsibility for the community service | |  |  |  |
| Ward-based nursing staff (This covers nursing staff on wards to which people with haemoglobin disorders are usually admitted) | |  |  |  |
| Day unit (or equivalent) nursing staff | |  |  |  |

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| 1. QS 2. HA - 205 3. HA - 206 | Medical Staffing and Competences: Unscheduled Care and Doctors in Training | **Y/N** | **Comments** |
| SHTs and HCCs only: Is there 24/7 consultant and junior staffing for unscheduled care available? | |  |  |
| If doctors in training are part of achieving QSs HC-204 or HC-205, then do they have the opportunity to gain competences in all aspects of the care of adults with haemoglobin disorders. | |  |  |

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| 1. QS 2. HA- 301 | Support Services | **Y/N** | **Comments** |
| * 1. Social worker/benefits adviser | |  |  |
| * 1. Leg ulcer service | |  |  |
| * 1. Dietetics | |  |  |
| * 1. Physiotherapy (inpatient and community-based) | |  |  |
| * 1. Occupational therapy | |  |  |
| * 1. Mental health services | |  |  |
| 1. QS 2. HA- 301 | Specialist Support - access to | **Y/N** | **Comments** |
| * 1. DNA studies | |  |  |
| * 1. Genetic counselling | |  |  |
| * 1. Sleep studies | |  |  |
| * 1. Diagnostic radiology | |  |  |
| * 1. Manual exchange transfusion (24/7) | |  |  |
| * 1. Automated red cell exchange transfusion (24/7) | |  |  |
| * 1. Pain team including specialist monitoring of patients with complex analgesia needs | |  |  |
| * 1. Level 2 and 3 critical care | |  |  |

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| **Guidelines and Protocols in place (these should also be made available /submitted prior to the review)** | | **Y/N** | **Review Date** |
| QS HA - 501 Transition Guidelines | |  |  |
| QS HA - 502 New Patient and Annual Review Guidelines | |  |  |
| QS HA - 503 Clinical Guidelines: LHT Management and Referral | |  |  |
| QS HA - 504 Transfusion Guidelines | |  |  |
| QS HA - 506 Chelation Therapy | |  |  |
| QS HA - 507 Hydroxycarbamide and Other Disease Modifying Therapies | |  |  |
| QS HA - 508 Non-Transfusion Dependent Thalassaemia (nTDT) | |  |  |
| QS HA - 509 Clinical Guidelines: Acute Complications | |  |  |
| QS HA - 510 Clinical Guidelines: Chronic Complications | |  |  |
| QS HA - 511 Anaesthesia and Surgery | |  |  |
| QS HA - 511 Fertility and Pregnancy | |  |  |
| 1. QS   HA - 705 | 1. SHT Audits | **Completed** | **Active** |
| The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) | |  |  |
| Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions | |  |  |
| 1. List participation in HCC agreed research trials | | **Completed** | **Active** |
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| **INNOVATIONS TO SHARE** |
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| **AREAS FOR DEVELOPMENT/CHALLENGES OVER THE NEXT TWO TO THREE YEARS** |
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| **ANY OTHER RELEVANT BACKGROUND INFORMATION** |
|  |

**Completed by**

Name:

Date:

1. *Recommended Staffing: National NHS England compliance exercise for designation of SHTs 2019.* [↑](#footnote-ref-1)
2. *Recommended Staffing: National NHS England compliance exercise for designation of SHTs 2019.* [↑](#footnote-ref-2)
3. *Recommended Staffing: National NHS England compliance exercise for designation of SHTs 2019.* [↑](#footnote-ref-3)
4. *Recommended Staffing: National NHS England compliance exercise for designation of SHTs 2019.* [↑](#footnote-ref-4)