



# Quality Standards

## Health Services for People with Haemoglobin Disorders

**Version 4**

**October 2018**



0831



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Review by: October 2021.at the latest

<b>Version No.</b>	<b>Date</b>	<b>Change from previous version</b>
V3	07.12.17	N/A
V3.1	01.03.18	Amended copyright paragraph to include UK Forum on Haemoglobin Disorders Minor amendments to grammar and cross references
V4	17.10.18	Review of literature. Minor amendments: <ul style="list-style-type: none"><li>• Wording of QS HN-199</li><li>• Change of term to 'Non-Transfusion Dependent Thalassaemia (nTDT)' QS-HN 510 and QS HY-502</li><li>• QS-HN-703 updated</li><li>• Evidence for compliance for meeting Trans Cranial Doppler U/S QS</li></ul>

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## INTRODUCTION

These Quality Standards were originally developed separately for children and adults' services to support implementation of the '*Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK*', *Sickle Cell Society (2018)* '*Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK*' (3rd edition 2015) and '*Sickle Cell Disease in Childhood Standards and Guidelines for Clinical Care*' (2<sup>nd</sup> Edition 2010). They have now been combined into a single set of Quality Standards for use in both children's and adult services.

Standards and guidance can be interpreted in different ways and may not always be implemented in full. These Quality Standards clarify the arrangements that should be in place and may provide the answer to the question: "For each service, how will I know that the '*Standards and Guidelines for Clinical Care*' have been implemented?" The Quality Standards are suitable for use in self-assessment or peer review visits. As with the *Standards* documents, these Quality Standards describe what services should be aiming to provide. All services should be working towards meeting all applicable Quality Standards within the next two to five years.

The Quality Requirements for Children's Services were developed between 2006 and 2008 and were used for a pilot visit to the Royal London Hospital in 2007 and for visits to 19 hospitals across England in 2010/11. Development of the adult Quality Standards took place during 2010 and 2011 through a sub-group of the UK Forum on Haemoglobin Disorders. Lessons learnt from the paediatric peer review process were taken into account and a section on network standards added. The adult Quality Standards were used in visits to 29 hospitals across England in 2012/13. The adult and children's' Quality Standards were then combined and used for visits to 33 children's and 33 adult services in 2014/16. Version 3 incorporated learning from the 2014/16 reviews. Version 4 has been updated with guidance published since the last review, including the haemoglobinopathy quality dashboard for 2018/19 and some changes to terminology and compliance. Version 4 of the Quality Standards will be used for the 2019/20 review programme. The outcomes of the consultation by Specialised Commissioning (NHS England) to improve specialised services for sickle cell and thalassaemia may change the configuration and terminology, and these Quality Standards may need a further revision when the outcomes of the consultation are published.

The Network Standards aim to improve the quality of care through:

- Establishment of effective network management groups which will develop and implement the strategy for individual networks in line with national policy.
- Clear leadership of networks with adequate time and support being given to network lead consultants, network lead nurses and network managers.
- Agreement and implementation of network-wide policies and pathways of care

These Network Standards need to be achieved in each network. Low prevalence areas are likely to have one specialist team which will also act as the focus for the work of the network. High prevalence areas may have sufficient patient numbers for several specialist teams to network together, along with hospitals providing local care closer to home, to achieve the Network Standards.

A full list of references on which the Quality Standards are based is given in Appendix 1. The Quality Standards are cross-referenced to the British Standards Institution PAS16:16 and the Care Quality Commission Key Lines of Enquiry in Appendix 2. A glossary of terms and abbreviations is given in Appendix 3.

## SCOPE OF THE QUALITY STANDARDS

These Quality Standards apply to all services caring for people with Haemoglobin Disorders and, to Networks and Commissioners.

These Quality Standards use the following abbreviations:

SHC     Specialist Haemoglobinopathy Centre

LHT Local Haemoglobinopathy Teams (or Linked Providers)

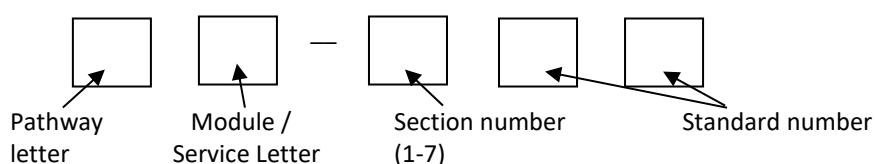
All All services

The Health Services for People with Haemoglobin Disorders Quality Standards should sit within organisations' overall clinical governance arrangements. The WMQRS Clinical Governance Quality Standards describe the clinical governance arrangements which should be in place and organisations may wish to use these to assure themselves of the robustness of their overall clinical governance arrangements.

## STRUCTURE OF THE QUALITY STANDARDS

### WMQRS QUALITY STANDARDS REFERENCE STRUCTURE

WMQRS Quality Standard reference numbers have the following structure:



Each Standard is structured as follows:

<b>Reference Number (Ref)</b>	This column contains the reference number for each Standard, which is unique to these Standards and is used for all cross-referencing. Each reference number is composed of two letters and three digits (see above and below for more detail).										
Applicability	The applicability of each Quality Standard to each type of service is shown underneath the reference number.										
Box showing how the QS will be reviewed	<p>The reference column also includes a guide to how the Standard will be reviewed:</p> <table border="1"> <tr> <td>BI</td> <td>Background information</td> </tr> <tr> <td>Visit</td> <td>Visiting facilities</td> </tr> <tr> <td>MP&amp;S</td> <td>Meeting service users (children, young people, adults) and staff</td> </tr> <tr> <td>CNR</td> <td>Case note review or clinical observation</td> </tr> <tr> <td>Doc</td> <td>Documentation should be available. Documentation may be written or be in the form of a website or other social media</td> </tr> </table> <p>The shaded area indicates the approach that will be used to reviewing the Quality Standard. APPENDIX 4 summarises the evidence needed for review visits.</p>	BI	Background information	Visit	Visiting facilities	MP&S	Meeting service users (children, young people, adults) and staff	CNR	Case note review or clinical observation	Doc	Documentation should be available. Documentation may be written or be in the form of a website or other social media
BI	Background information										
Visit	Visiting facilities										
MP&S	Meeting service users (children, young people, adults) and staff										
CNR	Case note review or clinical observation										
Doc	Documentation should be available. Documentation may be written or be in the form of a website or other social media										
<b>Quality Standard (QS)</b>	This describes the quality that services are expected to provide.										
<b>Notes</b>	<i>The notes give more detail about either the interpretation or the applicability of the Standard.</i>										

### Pathway and Service Letters:

These generic Standards use the pathway letter H. The Standards are in the following sections:

HN-	Specialist services for People with Haemoglobin Disorders
HY-	Haemoglobin Disorders: Network
HZ-	Haemoglobin Disorders: Commissioning

## Topic Sections:

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

Within each section, each Standard has a unique two digit number. These are not always sequential, to ensure that similar standards in different pathways have the same two digit number.

## Policies, Protocols, Guidelines and Procedures:

The Quality Standards use the words policy, protocol, guideline and procedure based on the following definitions:

**Policy:** A course or general plan adopted by an organisation, which sets out the overall aims and objectives in a particular area.

**Protocol:** A document laying down in precise detail the tests or steps that must be performed.

**Guidelines:** Principles which are set down to help determine a course of action. They assist the practitioner to decide on a course of action but do not need to be automatically applied. Clinical guidelines do not replace professional judgement and discretion.

**Procedure:** A procedure is a method of conducting business or performing a task, which sets out a series of actions or steps to be taken.

For simplicity, some standards use the term 'guidelines and protocols' which should be taken as referring to policies, protocols, guidelines and procedures. All clinical guidelines should be based on national guidance, including NICE guidance where available. Local guidelines and protocols should specify the way in which national guidance will be implemented locally and should show consideration of local circumstances. Guidelines and protocols should be organised in the way which is most helpful to the local service, for example, one guideline may cover several Quality Standards or several guidelines may relate to one Quality Standard.

## EXCEL AND PDF VERSIONS

Using the Excel version of the Quality Standards has the following advantages:

- Standards applicable to different types of Service (HN -\*\*\*) can be selected more easily by using the 'Filter' function and selecting the appropriate service in Columns B to D.
- The spreadsheet includes a 'CQC' tab. This updates automatically when a self-assessment is completed and allows services to see, and demonstrate, the extent to which they are achieving the CQC Key Lines of Enquiry.

When using the Excel spreadsheet it is useful to know the following:

- If the tabs at the bottom of the spreadsheet do not appear, please minimise the spreadsheet and then maximise it again and the tabs should be there.
- 'Alt' and 'Enter' (together) allows you to put a new line within an Excel cell.

The PDF version includes appendices 1 to 4 which are not included in the Excel version.

## COMMENTS ON THE QUALITY STANDARDS

The Quality Standards will be revised as new national guidance becomes available and as a result of experience of their use in peer review. Comments on the Quality Standards are welcomed and will be taken into account when they are updated. Comments should be sent to [wmqrs@nhs.net](mailto:wmqrs@nhs.net)

More information about WMQRS and its Quality Standards and reviews is available at [www.wmqrs.nhs.uk](http://www.wmqrs.nhs.uk) or 0121 612 2146.

## SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

Ref	Standard					
<h3>SUPPORT FOR SERVICE USERS AND THEIR CARERS</h3>						
<p>HN-101</p> <p>All</p> <table border="1" data-bbox="209 506 292 680"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Haemoglobin Disorder Service Information</b></p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> <li>a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services</li> <li>b. Clinic times and how to change an appointment</li> <li>c. Ward usually admitted to and its visiting times</li> <li>d. Staff of the service</li> <li>e. Community services and their contact numbers</li> <li>f. Relevant national organisations and local support groups</li> <li>g. Where to go in an emergency</li> <li>h. How to:             <ol style="list-style-type: none"> <li>i. Contact the service for help and advice, including out of hours</li> <li>ii. Access social services</li> <li>iii. Access benefits and immigration advice</li> <li>iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)</li> <li>v. Give feedback on the service, including how to make a complaint</li> <li>vi. Get involved in improving services (QS HN-199)</li> </ol> </li> </ol> <p><i>Note:</i>  <i>Information should be age appropriate, written in clear, plain English and should be available in formats and languages appropriate to the needs of patients and their carers. Information for children and young people should meet the 'You're Welcome – Quality criteria for young people friendly health services', (DH, 2011).</i></p>
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<p>HN-102</p> <p>All</p> <table border="1" data-bbox="209 1408 292 1583"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Information about Haemoglobin Disorders</b></p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> <li>a. A description of their condition (SC or T), how it might affect them and treatment available</li> <li>b. Problems, symptoms and signs for which emergency advice should be sought</li> <li>c. How to manage pain at home (SC only)</li> <li>d. Splenic palpation and Trans-Cranial Doppler scanning (children only)</li> <li>e. Transfusion and iron chelation</li> <li>f. Possible complications, including priapism and complications during pregnancy</li> <li>g. Health promotion, including:             <ol style="list-style-type: none"> <li>i. Travel advice</li> <li>ii. Vaccination advice</li> </ol> </li> <li>h. National Haemoglobinopathy Registry, its purpose and benefits</li> <li>i. Self-administration of medications and infusions</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. As QS HN-101.</li> <li>2. Information may be given at different stages of the patient pathway.</li> </ol>
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HN-103 All <table border="1" style="width: 100px; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Care Plan</b></p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> <li>a. An individual care plan or written summary of their annual review including:             <ol style="list-style-type: none"> <li>i. Information about their condition</li> <li>ii. Plan for management in the Emergency Department</li> <li>iii. Planned acute and long-term management of their condition, including medication</li> <li>iv. Named contact for queries and advice</li> </ol> </li> <li>b. A permanent record of consultations at which changes to their care are discussed</li> </ol> <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. Care plans may be in the form of clinic letters or patient-held records.</li> <li>2. For patients with sickle cell disease the plan for management in the Emergency Department should include baseline oxygen level, if abnormal, and pain management.</li> </ol>
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HN-104 All <table border="1" style="width: 100px; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Information for Primary Health Care Team</b></p> <p>Written information should be sent to the patient's primary health care team covering available local services and:</p> <ol style="list-style-type: none"> <li>a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)</li> <li>b. Side effects of medication, including chelator agents [SC and T]</li> <li>c. Guidance for GPs on:             <ol style="list-style-type: none"> <li>i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs)</li> <li>ii. Immunisations</li> <li>iii. Contraception and sexual health</li> </ol> </li> <li>d. Indications and arrangements for seeking advice from the specialist service</li> </ol> <p><i>Note:</i></p> <p><i>The guidance for GPs should be based on the agreed shared care guidelines (QS HN-505).</i></p>
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HN-105 SHC <table border="1" style="width: 100px; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)</b></p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> <li>a. Reason for the scan and information about the procedure</li> <li>b. Details of where and when the scan will take place and how to change an appointment</li> <li>c. Any side effects</li> <li>d. Informing staff if the child is unwell or has been unwell in the last week</li> <li>e. How, when and by whom results will be communicated</li> </ol> <p><i>Note:</i></p> <p><i>As QS HN-101.</i></p>
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<p>HN-106</p> <p>All</p> <table border="1" data-bbox="209 315 292 495"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>School Care Plan (Children’s Services Only)</b></p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> <li>School attended</li> <li>Medication, including arrangements for giving / supervising medication by school staff</li> <li>What to do in an emergency whilst in school</li> <li>Arrangements for liaison with the school</li> <li>Specific health or education need (if any)</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>This QS is not applicable to services for adults.</i></li> <li><i>‘School’ refers to nursery, school or college. This QS is applicable to all children and young people in full-time education.</i></li> </ol>
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<p>HN-194</p> <p>All</p> <table border="1" data-bbox="209 768 292 947"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Environment</b></p> <p>The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.</p> <p><i>Note:</i></p> <p><i>Evidence of admissions of patients to other clinical areas may be used in determining compliance with this QS.</i></p>
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<p>HN-195</p> <p>SHC</p> <table border="1" data-bbox="209 1104 292 1283"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Transition to Adult Services</b></p> <p>Young people approaching the time when their care will transfer to adult services should be offered:</p> <ol style="list-style-type: none"> <li>The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services</li> <li>A named coordinator for the transfer of care</li> <li>A preparation period prior to transfer</li> <li>Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>As QS HN-101</i></li> <li><i>This QS is normally applicable only to SHCs. If networks agree to transition directly to LHTs then this QS is applicable also to these teams. This QS applies to both adult and paediatric services as both need to be involved in the transfer of care.</i></li> </ol>
BI						
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Ref	Standard					
<p>HN-199</p> <p>All</p> <table border="1" data-bbox="209 315 292 495"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Involving Patients and Carers</b></p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> <li>Mechanisms for receiving feedback from patients and carers</li> <li>An annual patient survey (or equivalent)</li> <li>Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service</li> <li>Examples of changes made as a result of feedback and involvement of patients and carers</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>The arrangements may be part of Trust-wide mechanisms so long as issues relating to haemoglobin disorder services can be identified.</li> <li>It is desirable that paediatric and adult services collaborate on involving young people and obtaining feedback on transition arrangements.</li> <li>A validated tool for collecting views of patients may be used for compliance with 'b'</li> <li>A 10% response rate for annual patient surveys is the minimum expected for compliance with this QS.</li> </ol>
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<b>STAFFING</b>						
<p>HN-201</p> <p>All</p> <table border="1" data-bbox="209 1028 292 1207"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Lead Consultant</b></p> <p>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have an appropriate number of session/s identified for this role within their job plan and cover for absences should be available.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>For SHC's this role will involve liaison with LHTs across the network and with community services for local patients. For LHTs this role will involve liaison with the network SHC and with local community services.</li> <li>'Caring for haemoglobinopathy patients: Report of a national workforce survey.' (2015), UK Forum on Haemoglobin Disorders, recommends one Programmed Activity session per week for the clinical lead for a geographic area. The time required for this leadership role is additional to the consultant staffing appropriate for the number of patients being cared for by the service (QS HN-203).</li> <li>The lead consultant for services for children and young people may be a paediatrician or a paediatric haematologist.</li> <li>In SHCs, cover for absences of the lead consultant should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.</li> </ol>
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HN-202 All <table border="1" data-bbox="209 315 292 490"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Lead Nurse</b></p> <p>A lead nurse should be available with:</p> <ol style="list-style-type: none"> <li>Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders</li> <li>Responsibility for liaison with other services within the network</li> <li>Competences in caring for people with haemoglobin disorders</li> <li>Competences in the care of children and young people (children's services only)</li> </ol> <p>The lead nurse should have appropriate time for their leadership role and cover for absences should be available.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>For SHC's this role will involve liaison with LHTs across the network and with community services for local patients. For LHTs this role will involve liaison with the network SHC and with local community services.</i></li> <li><i>This QS is not specific about the arrangements for cover for absences and different arrangements will be appropriate in different sized services. These arrangements should ensure the quality of patient care is not adversely affected during absences of the lead nurse.</i></li> <li><i>RCN competences for nurses caring for people with haemoglobin disorders are available at <a href="http://www.rcn.org.uk/professional-development/publications/pub-003874">www.rcn.org.uk/professional-development/publications/pub-003874</a></i></li> </ol>
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<p>HN-204</p> <p>All</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Nurse Staffing and Competences</b></p> <p>The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> <li>a. Clinical nurse specialist/s with responsibility for the acute service</li> <li>b. Clinical nurse specialist/s with responsibility for the community service</li> <li>c. Ward-based nursing staff</li> <li>d. Day unit (or equivalent) nursing staff</li> <li>e. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion</li> </ol> <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>Clinical nurse specialist roles for acute and community services may be combined, especially in low prevalence areas.</i></li> <li>2. <i>This QS covers nursing staff on wards to which people with haemoglobin disorders are usually admitted.</i></li> <li>3. <i>The nurse specialist or counsellor who provides support for patients in the community may be employed by the SHC / LHT or may be provided through a Service Level Agreement with community services (QS HN-605).</i></li> <li>4. <i>RCN competences for nurses caring for people with haemoglobin disorders are available at <a href="http://www.rcn.org.uk/professional-development/publications/pub-003874">www.rcn.org.uk/professional-development/publications/pub-003874</a></i></li> <li>5. <i>Competences should be maintained through appropriate CPD. Documentation of CPD undertaken is not required but reviewers will ask about this.</i></li> <li>6. <i>Further guidance on nurse staffing levels and competences is being developed by the UK Forum on Haemoglobin Disorders and should be used to guide interpretation of this QS when available.</i></li> </ol>
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<p>HN-205</p> <p>All</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Psychology Staffing and Competences</b></p> <p>The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> <li>a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care</li> <li>b. Time for input to the service’s multi-disciplinary discussions and governance activities</li> <li>c. Provision of, or arrangements for liaison with and referral to, neuro-psychology</li> </ol> <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>This QS is not specific about the arrangements for cover for absences and different arrangements will be appropriate in different sized services.</i></li> <li>2. <i>Further guidance on psychology staffing levels and competences is being developed by the British Psychological Society Special Interest Group and should be used to guide interpretation of this QS when available. The interpretation of an appropriate staffing level used in the 2014-16 peer review visits was 1w.t.e. for 300 patients.</i></li> </ol>
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HN-207 SHC <table border="1" data-bbox="209 916 292 1095"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)</b></p> <p>Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Staff undertaking Trans-Cranial Doppler ultrasound should maintain a log book of the scans undertaken. Log books will need to be provided as evidence of compliance with this QS or the service may have a system of monitoring the number of scans undertaken. Annual assessment of competence may be through submission of a sample of scans to a training centre or through local peer review. (Trans-Cranial Doppler Scanning for Children with Sickle Cell Disease Standards and Guidance, 2016, UK Forum on Haemoglobin Disorders)</i></li> <li><i>This QS is not applicable if patients needing TCD ultrasounds are referred to another network for this procedure. It is applicable if TCD ultrasound is undertaken by another department, for example, by the imaging service.</i></li> </ol>
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<b>SUPPORT SERVICES</b>						
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HN-303 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Specialist On-site Support</b> <p>Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team:</p> <ol style="list-style-type: none"> <li>Manual exchange transfusion (24/7)</li> <li>Erythrocytapheresis</li> <li>Acute pain team including specialist monitoring of patients with complex analgesia needs</li> <li>High dependency care, including non-invasive ventilation</li> <li>Level 2 and 3 critical care</li> </ol> <p><i>Note:</i></p> <p>For paediatric services, the PICU (Level 3 Critical Care Unit) may not be on the same hospital site as the specialist team but referrals normally should be to a PICU with specialist expertise in the care of children and young people with haemoglobin disorders.</p>
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<b>FACILITIES AND EQUIPMENT</b>						
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<b>GUIDELINES AND PROTOCOLS</b>						
HN-501 SHC <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Transition Guidelines</b>  Guidelines on transition to adult care should be in use covering at least: <ol style="list-style-type: none"> <li>a. Age guidelines for timing of the transfer</li> <li>b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer</li> <li>c. Allocation of a named coordinator for the transfer of care</li> <li>d. A preparation period and education programme relating to transfer to adult care</li> <li>e. Communication of clinical information from paediatric to adult services</li> <li>f. Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. Guidelines should be based on NICE guidance or other evidence of effectiveness. Guidelines should normally be the same across a network (QS HY-5**).</li> <li>2. This QS is normally applicable only to SHCs. If networks agree to transition directly to LHTs then this QS is applicable also to these teams. This QS applies to both adult and paediatric services as both need to be involved in the transfer of care.</li> </ol>
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HN-503 LHT <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical Guidelines: LHT Management and Referral</b></p> <p>Guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>As QS HN-501 note 1</li> <li>LHT guidelines may be part of the guidelines in QS HN-504 to HN-510 or may be separate.</li> </ol>
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HN-507 All <table border="1" style="width: 100px; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Specialist Management Guidelines</b></p> <p>Guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> <li>a. During anaesthesia and surgery</li> <li>b. Who are pregnant</li> <li>c. Receiving hydroxycarbamide therapy</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. As QS HN-501 note 1</li> <li>2. Guidelines should be specific about differences between the care of sickle cell disease and thalassaemia and should be based on network-agreed guidelines.</li> </ol>
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HN-508 All <table border="1" style="width: 100px; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">MP&amp;S</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4f81bd; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical Guidelines: Chronic complications</b></p> <p>Guidelines on the management of chronic complications should be in use covering at least:</p> <ol style="list-style-type: none"> <li>a. Renal disease</li> <li>b. Orthopaedic problems</li> <li>c. Retinopathy</li> <li>d. Cardiological complications / pulmonary hypertension</li> <li>e. Chronic respiratory disease</li> <li>f. Endocrinopathies</li> <li>g. Neurological complications</li> <li>h. Chronic pain</li> <li>i. Liver disease</li> <li>j. Growth delay / delayed puberty (children only)</li> <li>k. Enuresis (children only)</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. As QS HN-501 note 1</li> <li>2. Guidelines should be based on NICE guidance or other evidence of effectiveness and on network agreed guidelines (HY-502).</li> </ol>
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HN-509 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)</b> Guidelines for referral for consideration of bone marrow transplantation should be in use. <i>Notes:</i> <ol style="list-style-type: none"> <li>As QS HN-501 note 1</li> <li>If access to bone marrow transplantation becomes available, then this QS will also be applicable to adult services.</li> </ol>
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HN-510 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Non-Transfusion Dependent Thalassaemia (nTDT)</b> Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: <ol style="list-style-type: none"> <li>Indications for transfusion</li> <li>Monitoring iron loading</li> <li>Indications for splenectomy</li> </ol> <i>Notes:</i> <ol style="list-style-type: none"> <li>As QS HN-501 note 1</li> <li>Indications for transfusion may be part of the transfusion guidelines in QS HN-504</li> <li>Indications for monitoring iron loading may be part of the guidelines on chelation therapy HN -505</li> </ol>
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HN-599 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Clinical Guideline Availability</b> Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas. <i>Notes:</i> <ol style="list-style-type: none"> <li>As QS HN-502.</li> <li>As QS HN-508</li> </ol>
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<b>SERVICE ORGANISATION AND LIAISON WITH OTHER SERVICES</b>						
HN-601 All <table border="1" data-bbox="209 427 292 602"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Service Organisation</b></p> <p>A service organisation policy should be in use covering arrangements for:</p> <ol style="list-style-type: none"> <li>'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a SHC (Children's SHC only)</li> <li>Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission</li> <li>Patient discussion at multi-disciplinary team meetings (QS HN-602)</li> <li>Arrangements for liaison with community paediatricians and with schools (children's services only)</li> <li>'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated (children's services only)</li> <li>Follow up of patients who do not attend</li> <li>Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care.</li> <li>Accessing specialist advice (QS HN-304)</li> <li>Two-way communication of patient information between SHC and LHTs</li> <li>If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together</li> </ol> <p><i>Note:</i> A senior decision-maker may be a consultant or middle-grade doctor in haematology or specialist nurse with appropriate competences.</p>
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HN-602 All <table border="1" data-bbox="209 1364 292 1538"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Multi-Disciplinary Meetings</b></p> <p>Multi-disciplinary team meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and representatives of support services (QS HN-301).</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Support services (QS HN-301) should be able to attend multi-disciplinary team meetings when required.</li> <li>Frequency of meetings is not defined and will depend on the number of patients cared for by the service. Membership of and attendance at multi-disciplinary meetings is not defined and will depend on the number and needs of patients cared for by the service.</li> </ol>
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HN-603 SHC <table border="1" data-bbox="209 1816 292 1991"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Delegation of Annual Reviews</b></p> <p>If annual reviews are undertaken by LHT/s on behalf of the SHC, a written agreement should be in place covering:</p> <ol style="list-style-type: none"> <li>Monitoring protocols (QS HN-502)</li> <li>LHT management and referral guidelines (QS HN-503)</li> <li>National Haemoglobinopathy Registry data collection (QS HN-701)</li> </ol>
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HN-605 All <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #0056b3; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Service Level Agreement with Community Services</b>  A service level agreement for support from community services should be in place covering, at least: <ol style="list-style-type: none"> <li>a. Role of community service in the care of patients with haemoglobin disorders</li> <li>b. Two-way exchange of information between hospital and community services.</li> </ol> <i>Note:</i> <i>This QS is not applicable when community and hospital services are managed as a single team.</i>
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HN-606 SHC <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #0056b3; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)</b>  A Standard Operating Procedure for Trans-Cranial Doppler ultrasound should be in use covering at least: <ol style="list-style-type: none"> <li>a. Trans-Cranial Doppler modality used</li> <li>b. Identification of ultrasound equipment and maintenance arrangements</li> <li>c. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-207)</li> <li>d. Arrangements for ensuring staff performing Trans-Cranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year</li> <li>e. Arrangements for recording and storing images and ensuring availability of images for subsequent review</li> <li>f. Reporting format</li> <li>g. Arrangements for documentation and communication of results</li> <li>h. Internal systems to assure quality, accuracy and verification of results</li> </ol> <i>Notes:</i> <ol style="list-style-type: none"> <li>1. <i>This QS is not applicable if patients needing TCD ultrasounds are referred to another network for this procedure. It is applicable if TCD ultrasound is undertaken by another department, for example, by the imaging service. The department providing the TCD service has the responsibility for compliance with this QS.</i></li> <li>2. <i>Guidelines should be specific about supervision of staff in training.</i></li> <li>3. <i>Internal quality assurance systems may include double-reading of a sample of results.</i></li> </ol>
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HN-607 All <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #0056b3; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Network Review and Learning Meetings</b>  At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).
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HN-608 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Neonatal Screening Programme Review Meetings</b> <p>The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (QS HN-703), identify issues of mutual concern and agree action.</p> <p><i>Note:</i>  <i>This QS is applicable to services for children and young people only.</i></p>
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<b>GOVERNANCE</b>						
HN-701 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>National Haemoglobinopathy Registry</b> <p>Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies and patients lost to follow up.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>NHR data collection is the responsibility of the SHC but may be delegated to LHTs. Networks should ensure SHCs are informed of all serious adverse events involving their patients.</i></li> <li><i>Serious adverse events are as defined in the National Haemoglobinopathy Registry: Acute chest syndrome, cardiac dysfunction, complications during or after pregnancy, death, end stage renal failure needing dialysis, hyperhaemolysis, other bacterial sepsis, pneumococcal sepsis, post-operative complication, stroke.</i></li> </ol>
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HN-702 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Activity Data</b> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> <li>Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances</li> <li>Length of in-patient stays</li> <li>Re-admission rate</li> <li>'Did not attend' rate for out-patient appointments</li> </ol>
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HN-704 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Other Quality Data</b></p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> <li>Proportion of children who have been offered treatment following Trans-Cranial Doppler Screening</li> </ol>
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HN-705 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Other Audits</b></p> <p>Clinical audits covering the following areas should have been undertaken within the last two years:</p> <ol style="list-style-type: none"> <li>Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies</li> <li>Whether all eligible patients on long term transfusion have been offered automated exchange transfusion</li> <li>Waiting times for elective:             <ol style="list-style-type: none"> <li>Phlebotomy</li> <li>Cannulation</li> <li>Setting up of the blood transfusion (for pre-ordered blood)</li> </ol> </li> </ol> <p><i>Note:</i> Evidence of audit should include 'closing the loop'.</p>
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HN-708 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Trans-Cranial Doppler Quality Assurance (Children's Services Only)</b></p> <p>The service should monitor and review at least annually:</p> <ol style="list-style-type: none"> <li>Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-207)</li> <li>Results of internal quality assurance systems (QS HN-606)</li> <li>Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)</li> </ol> <p><i>Note:</i>  <i>This QS is not applicable if patients needing TCD ultrasounds are referred to another network for this procedure. It is applicable if TCD ultrasound is undertaken by another department, for example, by the imaging service. The department providing the TCD service has the responsibility for compliance with this QS.</i></p>
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HN-798 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Review and Learning</b></p> <p>The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include:</p> <ol style="list-style-type: none"> <li>Review of any patient with a serious adverse event or who died</li> <li>Review of any patients requiring admission to a critical care facility</li> <li>Annual review of trends in National Haemoglobinopathy Registry data, activity data, Quality Dashboard, other quality data and other audits (Qs HN-701 to HN-705)</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>These arrangements should include feedback to operational staff and should link with Trust-wide (or equivalent) governance arrangements.</i></li> <li><i>As QS HN-701.</i></li> </ol>
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HN-799 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Document Control</b></p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p> <p><i>Note:</i>  <i>Specific documentary evidence of compliance is not required. This QS will be determined from the other documentary information provided. Copies of Trust document control policies are required.</i></p>
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## HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Quality Standards for Haemoglobin Disorders Clinical Networks are given separately from those for Specialist Haemoglobinopathy Centres. These Standards are the responsibility of Specialist Haemoglobinopathy Centres but, by agreement, the functions may be delegated to another organisation or coordinating group.

Ref	Standard					
<b>SUPPORT FOR SERVICE USERS AND THEIR CARERS</b>						
<b>HY-199</b> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Involving Patients and Carers</b> <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p>
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<b>STAFFING</b>						
<b>HY-201</b> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Network Leads</b> <p>The network should have a nominated:</p> <ol style="list-style-type: none"> <li>Lead consultant and deputy</li> <li>Lead specialist nurse for acute care</li> <li>Lead specialist nurse for community services</li> <li>Lead manager</li> <li>Lead for service improvement</li> <li>Lead for audit</li> <li>Commissioner</li> </ol> <p><i>Note:</i>  <i>Network leads are not expected to be full-time roles but should have sufficient time within their job plan for their role within the network.</i></p>
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<b>HY-202</b> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Education and Training</b> <p>The network should have agreed a programme of education and training to help services achieve compliance with QS HN-206.</p>
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## GUIDELINES AND PROTOCOLS

HY-501

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### Transition Guidelines

Network guidelines on transition to adult care should have been agreed covering:

- a. Age guidelines for timing of the transfer
- b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer
- c. Allocation of a named coordinator for the transfer of care
- d. Communication of clinical information from paediatric to adult services
- e. Arrangements for monitoring during the time immediately after transfer to adult care
- f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)

Guidelines should be explicit about transition directly to LHTs.

*Notes:*

1. *Transition guidelines should have been agreed with the paediatric service/s from which young people are usually transferred*
2. *Implementation of these guidelines is covered in QS HN-501.*

HY-502

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### Clinical Guidelines

Network guidelines should have been agreed covering:

- a. Annual review (QS HN-502)
- b. Routine monitoring (QS HN-502 and HN-503)
- c. Transfusion (QS HN-504)
- d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505)
- e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-304)
- f. Specialist management (QS HN-507)
- g. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-304)
- h. Non-Transfusion Dependent Thalassaemia (QS HN-510)

Guidelines should be explicit about any LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.

*Note:*

*Any detail expected, and implementation of these guidelines, is covered in QS HN-501 to HN-510.*

## SERVICE ORGANISATION AND LIAISON WITH OTHER SERVICES

HY-601

BI
Visit
MP&S
CNR
Doc

### Network Multi-Disciplinary Discussion

Arrangements for network-wide review and discussion of more complex patients should be in place, including agreed criteria for discussion of patients. LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved.

*Notes:*

1. *All SHCs in the network should be involved in the network-wide discussions. LHTs may participate only for the patients with which they are involved.*
2. *Multi-disciplinary discussion may be through face to face meetings, video-conference or a combination of mechanisms.*

## GOVERNANCE

<p><b>HY-701</b></p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Ongoing Monitoring</b></p> <p>The network should monitor on a regular basis:</p> <ol style="list-style-type: none"> <li>Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701)</li> <li>Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year</li> <li>Network-wide activity levels (HN-702)</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p><b>HY-702</b></p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Audit</b></p> <p>The network should have an agreed programme of audit and review covering network-wide achievement of Qs HN-703, HN-704 and HN-705.</p> <p><i>Note:</i> <i>These topics should be covered by the overall audit programme. Annual network audit is not expected.</i></p>
BI						
Visit						
MP&S						
CNR						
Doc						
<p><b>HY-703</b></p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Research</b></p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> <li>A policy on access to research relating to the care of patients with haemoglobin disorders</li> <li>A list of research trials available to all patients within the network.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p><b>HY-798</b></p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Network Review and Learning</b></p> <p>The SHC should meet at least twice a year with its referring LHT teams to:</p> <ol style="list-style-type: none"> <li>Identify any changes needed to network-wide policies, procedures and guidelines</li> <li>Review results of audits undertaken and agree action plans</li> <li>Review and agree learning from any positive feedback or complaints involving liaison between teams</li> <li>Review and agree learning from any critical incidents or ‘near misses’, including those involving liaison between teams</li> <li>Consider the content of future training and awareness programmes (QS HY-202)</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

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## COMMISSIONING

Quality Standards are the responsibility of NHS England specialised services commissioners working with Clinical Commissioning Group commissioners of local services.

Ref	Standard
HZ-601 BI Visit MP&S CNR Doc	<p><b>Commissioning of Services</b></p> <p>Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to the SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular:</p> <ol style="list-style-type: none"> <li>Designated SHC/s for the care of people with sickle cell disease</li> <li>Designated SHC/s for the care of adults with thalassaemia</li> <li>Any agreements for delegation of annual reviews to LHTs for care of people with sickle cell disease or thalassaemia</li> <li>Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia</li> <li>Community care providers</li> </ol>
HZ-701 BI Visit MP&S CNR Doc	<p><b>Clinical Quality Review Meetings</b></p> <p>Commissioners should review at least annually the quality of care provided by each SHC including at least:</p> <ol style="list-style-type: none"> <li>National Haemoglobinopathy Registry data collection (QS HN-701)</li> <li>Quality Dashboard (QS HN-703)</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>SHC representatives should have the opportunity to attend the Clinical Quality Review Meeting at which the quality of care provided by their service is discussed with commissioners.</i></li> <li><i>In networks with more than one SHC, or overlapping networks, Clinical Quality Review Meetings may be combined.</i></li> </ol>

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## APPENDIX 1 REFERENCE SOURCES

Year	Publisher	Title	Number
2018	NHS England	2018-19 Haemoglobinopathy Quality Dashboard	1.
2018	Sickle Cell Society	Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK -2018 . <a href="https://www.sicklecellsociety.org/resources/">https://www.sicklecellsociety.org/resources/</a>	2.
2018	Public Health England, Sickle Cell Society, UK Thalassaemia Society	Parents' Stories: Personal experiences of the NHS Antenatal Sickle Cell and Thalassaemia Screening Programme	3.
2018	Royal College of Paediatrics and Child Health	The State of Child Health: One Year On	4.
Accessed 2018	NHS Leadership Academy	Healthcare Leadership Model: The nine dimensions of leadership behaviour. Version 1.0 <a href="http://www.leadershipacademy.nhs.uk/">www.leadershipacademy.nhs.uk/</a>	5.
2017	NHS England	Next Steps on the Five Year Forward View	6.
2016	WMQRS and UK Forum on Haemoglobin Disorders	Services for People with Haemoglobin Disorders Peer Review Programme 2014-16 Overview Report	7.
2016	NHS England	Clinical Commissioning Policy16070/P: Treatment of iron overload for transfused and non-transfused patients with chronic inherited anaemias.	8.
2016	UK Forum on Haemoglobin Disorders	Transcranial Doppler Scanning for Children with Sickle Cell Disease Standards and Guidance (2 <sup>nd</sup> Edition)	9.
2016	United Kingdom Thalassaemia Society	Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (3 <sup>rd</sup> Edition)	10.
2015	UK Forum on Haemoglobin Disorders	Caring for haemoglobinopathy patients: Report of a national workforce survey	11.
2015	Care Quality Commission	Guidance for providers on meeting the regulations	12.
2014	National Institute for Health and Care Excellence	Sickle cell disease Quality standard [QS58]	13.
2013	WMQRS and UK Forum on Haemoglobin Disorders	Services for Adults with Haemoglobin Disorders Peer Review Programme 2012-13 Overview Report	14.
2013	NHS England	2013/14 NHS Standard Contract for Specialised Services for Haemoglobinopathy Care	15.
2013	European Network for Rare and Congenital Anaemias	Haemoglobinopathies on the Move: Is Europe ready?	16.

Year	Publisher	Title	Number
	(ENERCA), Thalassaemia International Federation and International Organisation for Migration (IOM)	Health and Migration Policy Perspectives	
2012	National Institute for Health and Care Excellence	Sickle cell disease: managing acute painful episodes in hospital. Clinical guideline [CG143]	17.
2012	NHS Sickle Cell and Thalassaemia Screening Programme	NHS Sickle Cell and Thalassaemia Screening Programme: Handbook for Laboratories	18.
2011	NHS Sickle Cell & Thalassaemia Screening Programme	NHS Sickle Cell and Thalassaemia Screening Programme; Standards for the Linked Antenatal and Newborn Screening Programme – Summary of Changes	19.
2011	Royal College of Nursing	Caring for people with sickle cell disease and thalassaemia syndromes – A framework for nursing staff	20.
2011	Department of Health	Quality Services for Young People Friendly Health Services	21.
2011	NHS Sickle Cell & Thalassaemia Screening Programme	Standards for the linked Antenatal and Newborn Screening Programme	22.
2010	NHS Sickle Cell and Thalassaemia Screening Programme	Sickle Cell Disease In Childhood Standards and Guidelines for Clinical Care, 2 <sup>nd</sup> Edition.	23.
2008	NCEPOD	A sickle crisis? A report of the National Confidential Enquiry in Patient Outcome and Death report	24.



The table below shows the links between the Quality Standards and generic guidance documents. Quality Standards without a reference source are based on other WMQRS Quality Standards, taking into account comments received.

QS reference	Guidance documents	QS reference	Guidance documents	QS reference	Guidance documents
HN-101	2,6,7,10,12,14,21,17,24	HN-304	2,6,7,10,12,14,18,	HN-701	1,2,7,10,12,14,23, 24
HN-102	2,3,7,10,12,14,20,21,23	HN-401	2,7,10,12,14,18	HN-702	1,2,7,10,12,14,23, 24
HN-103	2,4,7,12,14,24	HN-402	2,7,10,12,14,18,	HN-703	1,2,7,10,12,14,18,23, 24
HN-104	2,7,10,12,14,21,23,24	HN-501	2,6,7,10,12,14,21,23	HN-704	2,7,10,12,14,18,19,16,23, 24
HN-105	2,7,12,14,23	HN-502	7,12,14	HN-705	2,7,10,12,14,23
HN-106	2,4,7,10,12,14,23	HN-503	2,6,7,10,12,14,17,23, 24	HN-706	2,7,12,14,23
HN-194	2,7,10,12,14,18	HN-504	2,7,8,10,12,14,18,23	HN-707	7,9,12,14
HN-195	2,6,7,10,12,14,21,23	HN-505	7,8,10,12,14,18		
HN-199	2,7,10,12,14,21,23	HN-506	2,7,8,10,12,13,14,17,23, 24	HN-708	2,7,9,10,14,16,18,23, 24
HN-201	2,5,7,11,12,14,20,23,24	HN-507	2,7,10,12,14,17,23,	HN-798	1,2,7,12,14,24
HN-202	2,5,7,11,12,14,23	HN-508	2,7,8,10,12,14,17,23	HN-799	7,12,14
HN-203	2,5,7,11,12,14,20,23,24	HN-509	7,10,12,13,14,23	HY-199	2,7,12,14,23
HN-204	2,5,7,10,12,11,14,16,20, 23, 24	HN-510	7,12,14,18	HY-201	2,7,12,14,20,23, 24
HN-205	2,3,7,10,11,12,14,16,23,24	HN-511	2,7,12,14,23	HY-202	2,7,12,14,23,
HN-206	2,3,5,7,10,12,14,23, 24	HN-512	7,9,12,14	HY-501	2,7,10,12,14,18,21,22
HN-207	2,7,12,14,23	HN-601	2,7,10,12,14,18,23, 24	HY-502	2,7,10,12,13,14,17,18,23, 24
HN-208	7,12,14,21	HN-602	2,7,10,12,14, 24	HY-701	1,2,7,10,12,14,23, 24
HN-209	7,12,14,23	HN-603	1,2,7,12,14,	HY-702	2,7,10,12,14,23, 24
HN-210	7,9,12,14	HN-604	2,7,12,14,	HY-703	2,7,12,14,23
HN-299	7,12,14	HN-605	2,7,12,14,18,19,22	HY-798	2,7,10,12,14, 24
HN-301	6,7,10,12,14,16,21,23	HN-606	2,7,9,10,14,16,18,23, 24	HZ-601	2,7,6,10,12,14,15
HN-302	7,10,12,14,23,2,24	HN-607	2,7,10,12,14, 24	HZ-701	1,2,7,10,6,14,15,
HN-303	2,7,10,12,14,18	HN-608	2,3,10,13,22,23		

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## APPENDIX 2 CROSS-REFERENCES TO BRITISH STANDARDS INSTITUTION PAS16:16 AND CARE QUALITY COMMISSION KEY LINES OF ENQUIRY

The tables below show with an 'x' where a WMQRS Quality Standard addresses one of the following:

### 1. British Standards Institution PAS1616:2016 Healthcare – Provision of Clinical Services Specification

Ref	Requirements for the provision of clinical services
3	Leadership, strategy and management
4	Operational delivery of the clinical service
5	Systems to support clinical service delivery
6	Person-centred treatment and/or care
7	Risk and safety
8	Clinical effectiveness
9	Clinical service users with complex needs
10	Staffing a clinical service
11	Improvement, innovation and transformation
12	Educating the future workforce

### 2. Care Quality Commission's Key Lines of Enquiry (June 2017)

Ref	CQC Five Key Line of Enquiry
S	Are they safe?
E	Are they effective?
C	Are they caring?
R	Are they responsive?
W	Are they well-led?

Ref	British Standards Institute PAS 1616: 2016 3-12	CQC Five Key of Enquiry Questions																									
		Safe					Effective						Caring			Responsive				Well-Led							
		S 1	S 2	S 3	S 4	S 5	S 6	E 1	E 2	E 3	E 4	E 5	E 6	C 1	C 2	C 3	R 1	R 2	R 3	R 4	W 1	W 2	W 3	W 4	W 5	W 6	W 7
HN-101	6	x			x			x				x	x	x	x				x								
HN-102	6	x			x			x				x	x	x	x												
HN-103	6		x	x				x			x	x	x	x	x		x	x									
HN-104	6	x			x			x				x	x	x	x					x							
HN-105	6	x			x			x				x	x	x	x					x							
HN-106	6	x	x	x				x			x	x	x	x	x			x									
HN-194	5	x		x				x									x										
HN-195	6		x	x				x			x	x	x	x	x		x	x									
HN-199	3, 7, 6	x					x								x				x								x
HN-201	3, 4, 10,12		x					x			x										x				x	x	
HN-202	3, 4, 10,12		x					x			x										x				x	x	
HN-203	4, 10, 12		x					x			x										x	x	x		x	x	
HN-204	4, 10, 12		x					x			x										x	x	x		x	x	
HN-205	4, 10, 12		x					x			x										x	x	x		x	x	
HN-206	4, 10, 12		x					x			x										x	x	x		x	x	
HN-207	4, 10, 12		x					x			x										x	x	x		x	x	
HN-299	4, 10,12		x								x											x	x				
HN-301	4, 5, 6, 8		x					x			x	x						x	x								
HN-302	4, 10, 12		x					x			x										x	x	x		x	x	
HN-303	4, 5, 6, 8		x					x			x	x						x	x								
HN-304	4, 5, 6, 8, 9		x					x			x	x								x	x	x					
HN-305	4, 5, 6, 7, 8	x	x	x				x			x	x								x	x						
HN-401	5,7	x		x				x											x								
HN-501	6, 8.2, 9		x	x	x			x			x				x						x						

Ref	British Standards Institute PAS 1616: 2016 3-12	CQC Five Key of Enquiry Questions																											
		Safe					Effective						Caring			Responsive				Well-Led									
		S 1	S 2	S 3	S 4	S 5	S 6	E 1	E 2	E 3	E 4	E 5	E 6	C 1	C 2	C 3	R 1	R 2	R 3	R 4	W 1	W 2	W 3	W 4	W 5	W 6	W 7	W 8	
HN-502	6, 8.2, 9		x					x				x	x	x	x														
HN-503	6, 8.2, 9		x					x				x	x	x	x														
HN-504	6, 8, 9			x									x						x										
HN-505				x									x						x										
HN-506	6, 8.2, 9		x					x				x	x	x	x														
HN-507	6, 8.2, 9		x					x				x	x	x	x														
HN-508	6, 8.2, 9		x					x				x	x	x	x														
HN-509	4, 6, 8.2, 9		x					x		x	x	x	x	x	x														
HN-510	6, 8.2, 9		x					x				x	x	x	x														
HN-599	6, 8.2, 9		x					x				x	x	x	x														
HN-601	6, 7, 8, 9, 10, 11, 12			x		x	x	x			x			x	x		x	x	x					x	x	x	x	x	
HN-602	4, 6, 8, 9			x				x	x	x	x				x														
HN-603	3, 4, 6, 8, 9			x								x														x			
HN-604	4, 6, 8, 9							x																		x			
HN-605	4, 6, 9							x										x		X						x			
HN-606	4, 6, 8, 8.2, 9		x	x				x				x	x	x	x											x			
HN-607	3.2, 4, 7, 8, 11				x	x	x	x	x												x				x	x	x	x	
HN-608	4, 6, 8, 9			x				x																		x			
HN-701	3.2, 4, 7, 8,11					x	x	x	x																x	x	x	x	
HN-702	3.2, 4, 7, 8,11					x	x	x	x																x	x	x	x	
HN-703	3.2, 4, 7, 8,11					x	x	x	x																x	x	x	x	
HN-704	3.2, 4, 7, 8,11					x	x	x	x																x	x	x	x	
HN-705	3.2, 4, 7, 8,11					x	x	x	x																	x	x	x	x

Ref	British Standards Institute PAS 1616: 2016 3-12	CQC Five Key of Enquiry Questions																										
		Safe					Effective						Caring			Responsive				Well-Led								
		S 1	S 2	S 3	S 4	S 5	S 6	E 1	E 2	E 3	E 4	E 5	E 6	C 1	C 2	C 3	R 1	R 2	R 3	R 4	W 1	W 2	W 3	W 4	W 5	W 6	W 7	W 8
HN-706	3.2, 4, 7, 8,11					X	X	X	X															X	X	X	X	X
HN-707	3.2, 4, 6, 7, 8, 9, 11					X	X	X	X															X	X	X	X	X
HN-708	3.2, 4, 7, 8,11					X	X	X	X												X		X	X	X	X	X	
HN-798	3.2, 4, 7, 8, 11				X	X	X	X	X										X			X	X	X	X	X	X	
HN-799	5			X																								
HY-199	3, 7, 6	X					X							X				X								X		
HY-201	3, 4, 10,12		X					X		X										X				X	X			
HY-202	4, 10, 12		X					X		X										X	X	X		X	X			
HY-501	6, 8, 9	X	X	X				X			X			X			X						X					
HY-502	6, 8.2, 9		X					X			X	X	X	X														
HY-601	6, 9																											
HY-701	3.2, 4, 7, 8, 11					X	X	X	X												X		X	X	X	X	X	
HY-702	3.2, 4, 7, 8, 11					X	X	X	X														X	X	X	X	X	
HY-703	3.2, 4, 6, 7, 8, 9, 11					X	X	X	X														X	X	X	X	X	
HY-798	3.2, 4, 7, 8, 11				X	X	X	X	X										X			X	X	X	X	X	X	
HZ-601	3, 6, 7, 8, 9, 10, 11			X	X			X			X	X				X	X	X			X		X					
HZ-701	3.2, 4, 7, 8,11					X	X	X	X														X	X	X	X	X	

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## APPENDIX 3 GLOSSARY OF TERMS AND ABBREVIATIONS

Glossary of terms and abbreviations	
<b>Advocacy</b>	Advocacy means to speak up for someone. It is about making things change because people's voices are heard and listened to. It's about making sure that people can make their own choices in life and have the chance to be as independent as they want to be.
<b>BI</b>	Background information to review team.
<b>CAMHS</b>	Child & Adolescent Mental Health Services
<b>Carer</b>	Throughout the Quality Standards the term 'carer' applies to both family carers and paid carers or support workers.
<b>CCG</b>	Clinical Commissioning Group.
<b>Commissioner</b>	A commissioner decides how NHS and / or social care resources are spent, with the aim of improving health, reducing inequalities, and enhancing patient experience.
<b>CNR</b>	Case note review or clinical observation.
<b>CPA</b>	Clinical Pathology Accreditation
<b>CPD</b>	Continuing Professional Development
<b>CQC</b>	The Care Quality Commission is the independent regulator of health and social care in England.
<b>DH</b>	Department of Health.
<b>DNA studies</b>	Genetic studies for Deoxyribonucleic acid to give genealogical information on a patient's condition
<b>Doc</b>	Documentation should be available. Documentation may be in the form of a website or other social media.
<b>ENT</b>	Ear Nose and Throat
<b>GP</b>	A GP is a medical doctor, sometimes called a family doctor. They are usually the first person patients see for their health care, and they help patients to access other services.
<b>HbSB</b>	Sickle cell–haemoglobin C
<b>HbSS</b>	Sickle cell–haemoglobin S
<b>HealthWatch</b>	The 'consumer champion' for both health and adult social care and should be the independent, influential and effective local voice of the public on health issues.
<b>LBR</b>	Learning beyond registration.
<b>LHT</b>	Local Haemoglobinopathy Teams (or Linked Providers)
<b>mg/gm/DW</b>	Calculation formula –milligram/gram/dry weight
<b>MHRA</b>	Medicines and Healthcare Products Regulatory Agency
<b>MRI</b>	Magnetic resonance imaging
<b>MP&amp;S</b>	Meeting patients, carers and staff.
<b>NEQAS</b>	National External Quality Assessment Service
<b>NHR</b>	National Haemoglobinopathy Registry
<b>NHSLA</b>	NHS Litigation Authority.
<b>NICE</b>	National Institute for Health and Care Excellence.
<b>NQAS</b>	National Quality Assurance Scheme
<b>NVQ</b>	National Vocational Qualification.

Glossary of terms and abbreviations	
<b>PA</b>	Programmed Activity
<b>PALS</b>	Patient Advice and Liaison Service
<b>PDR</b>	Performance Development Review.
<b>PICU</b>	Paediatric Intensive Care Unit
<b>Provider</b>	A health or social care organisation which provides services to patients.
<b>QS</b>	Quality Standard.
<b>RCN</b>	Royal College of Nursing
<b>SC</b>	Sickle Cell
<b>School</b>	Nursery, school or college
<b>Service provider</b>	See 'Provider'.
<b>Service commissioner</b>	See 'Commissioner'.
<b>SHC</b>	Specialist Haemoglobinopathy Centre
<b>T</b>	Thalassaemia
<b>TCD</b>	Trans-Cranial Doppler
<b>Trust</b>	A NHS Trust, NHS Foundation Trust or other organisation with management responsibility for the service.
<b>UKAS</b>	UK Accreditation Service
<b>WMQRS</b>	West Midlands Quality Review Service
<b>w.t.e.</b>	Whole time equivalent

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## APPENDIX 4 PRESENTATION OF EVIDENCE FOR PEER REVIEW VISITS

Each Quality Standard reference column includes a box which illustrates how compliance will be reviewed.

Quality Standard reference column	
<b>Background information</b>	This means that the information should be included in the background report or self-assessment.
<b>Visiting facilities</b>	Reviewers will look for the information while they are visiting the service.
<b>Meeting patients, carers and staff</b>	These Standards will be discussed with patient, carers and /or staff as appropriate.
<b>Case note review or clinical observation</b>	A few Quality Standards require reviewers to look at case notes or other clinical information.
<b>Documentation</b>	These are policies, guidelines and other documentation that reviewers will need to see. Documentation may be in the form of a website or other social media.

The following table summarises the evidence needed for each Quality Standard.

QS Ref. No	QS Short Title	Background report	Visit	Meeting patients & staff	Case note review or clinical observation	Documentation needed	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
HN-101	<b>Haemoglobin Disorder Service Information</b>		X	X		X	Service information
HN-102	<b>Information about Haemoglobin Disorders</b>		X	X		X	Condition specific information
HN-103	<b>Care Plan</b>			X	X	X	Example of care plan or template
HN-104	<b>Information for Primary Health Care Team</b>			X	X	X	Primary Care team information
HN-105	<b>Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)</b>		X	X		X	TCD information
HN-106	<b>School Care Plan (Children's Services Only)</b>			X		X	Example of school care plan or template
HN-194	<b>Environment</b>		X	X			
HN-195	<b>Transition to Adult Services</b>		X	X		X	Transition information



QS Ref. No	QS Short Title	Background report	Visit	Meeting patients & staff	Case note review or clinical observation	Documentation needed	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
HN-199	<b>Involving Patients and Carers</b>			X		X	Examples of methods of receiving feedback. Examples of changes made as a result of feedback
HN-201	<b>Lead Consultant</b>	X					
HN-202	<b>Lead Nurse</b>	X		X			
HN-203	<b>Medical Staffing and Competences</b>			X		X	Competence framework describing the competences expected for roles within the service.
HN-204	<b>Nurse Staffing and Competences</b>			X		X	Competence framework describing the competences expected for roles within the service.
HN-205	<b>Psychology Staffing and Competences</b>			X		X	Competence framework describing the competences expected for roles within the service.
HN-206	<b>Training Plan</b>			X		X	Training plan including achievement of competences expected for roles within the service
HN-207	<b>Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)</b>			X		X	Monitoring records and log books for individual practitioners
HN-299	<b>Administrative, Clerical and Data Collection Support</b>	X					
HN-301	<b>Support Services</b>	X		X			
HN-302	<b>Emergency Department – Staff Competences</b>	X		X		X	Documentation of training undertaken and discussion of audits of compliance with NICE Clinical Guideline on the management of acute pain
HN-303	<b>Specialist On-site Support</b>	X		X			

QS Ref. No	QS Short Title	Background report	Visit	Meeting patients & staff	Case note review or clinical observation	Documentation needed	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
HN-304	<b>Specialist Services – Network</b>	X		X			
HN-305	<b>Laboratory Services</b>			X			
HN-401	<b>Facilities and Equipment</b>		X				
HN-501	<b>Transition Guidelines</b>			X	X	X	Guidelines
HN-502	<b>Monitoring Protocols</b>			X	X	X	Examples of checklists
HN-503	<b>Clinical Guidelines: LHT Management and Referral</b>			X	X	X	Monitoring and management guidelines
HN-504	<b>Transfusion Guidelines</b>			X	X	X	Guidelines
HN-505	<b>Chelation Therapy</b>			X	X	X	Clinical guidelines
HN-506	<b>Clinical Guidelines: Acute Complications</b>			X	X	X	Clinical guidelines
HN-507	<b>Specialist Management Guidelines</b>			X	X	X	Clinical guidelines
HN-508	<b>Clinical Guidelines: Chronic Complications</b>			X	X	X	Clinical guidelines
HN-509	<b>Referral for Consideration of Bone Marrow Transplantation (Children’s Services Only)</b>					X	Referral guidelines
HN-510	<b>Non-Transfusion Dependent Thalassaemia (nTDT)</b>					X	Clinical guidelines
HN-599	<b>Clinical Guideline Availability</b>			X			
HN-601	<b>Service Organisation</b>					X	Service organisation policy
HN-602	<b>Multi-Disciplinary Meetings</b>					X	Minutes of meetings held within the service. Meeting records showing percentage of meetings attended by staff.
HN-603	<b>Delegation of Annual Reviews</b>			X		X	Written agreement between SHC and LHT

QS Ref. No	QS Short Title	Background report	Visit	Meeting patients & staff	Case note review or clinical observation	Documentation needed	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
HN-604	<b>Out of Hours Elective Care</b>			X			
HN-605	<b>Service Level Agreement with Community Services</b>					X	Service level agreement
HN-606	<b>Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)</b>					X	Trans-cranial doppler ultrasound guidelines
HN-607	<b>Network Review and Learning Meetings</b>					X	Minutes of meetings
HN-608	<b>Neonatal Screening Programme Review Meetings</b>					X	Minutes of meetings
HN-701	<b>National Haemoglobinopathy Registry</b>			X		X	National Haemoglobinopathy Registry data reports
HN-702	<b>Activity Data</b>	X				X	Examples of data showing compliance with QS
HN-703	<b>Quality Dashboard</b>			X		X	Examples of data showing compliance with QS
HN-704	<b>Other Quality Data</b>			X		X	Examples of data showing compliance with QS
HN-705	<b>Other Audits</b>					X	Audit programme or plan Examples of completed audits, action plans and monitoring, including 'closing the loop'.
HN-706	<b>Network Audits</b>			X		X	Evidence of completion of planned audits, including 'closing the loop'
HN-707	<b>Research</b>	X				X	A list of trials participated in in the last three years and the number of patients recruited into trials

QS Ref. No	QS Short Title	Background report	Visit	Meeting patients & staff	Case note review or clinical observation	Documentation needed	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
HN-708	<b>Trans-Cranial Doppler Quality Assurance (Children's Services Only)</b>					X	Evidence of quality monitoring and log books for individual practitioners
HN-798	<b>Review and Learning</b>			X		X	Documentation depends on local arrangements, for example, minutes of review and learning meetings held within the service.
HN-799	<b>Document Control</b>					X	Compliance determined from other documentation presented
HY-199	<b>Involving Patients and Carers</b>			X		X	Examples of methods of receiving feedback. Examples of changes made as a result of feedback
HY-201	<b>Network Leads</b>	X					
HY-202	<b>Education and Training</b>			X		X	Education and training programme
HY-501	<b>Transition Guidelines</b>			X	X	X	Guidelines
HY-502	<b>Clinical Guidelines</b>			X	X	X	Clinical guidelines
HY-601	<b>Network Multi-Disciplinary Discussion</b>			X		X	Minutes of meetings
HY-701	<b>Ongoing Monitoring</b>			X		X	Quality monitoring report
HY-702	<b>Audit</b>			X		X	Audit programme
HY-703	<b>Research</b>			X		X	Research policy
HY-798	<b>Network Review and Learning</b>			X		X	Documentation depends on local arrangements, for example, minutes of review and learning meetings held within the network.
HZ-601	<b>Commissioning of Services</b>			X		X	Service commissioning plans
HZ-701	<b>Clinical Quality Review Meetings</b>					X	Notes of meetings

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