



UK Forum on
Haemoglobin
Disorders

Quality Standards

Health Services for people with Haemoglobin Disorders

Version 4.3

July 2021

These Quality Standards were developed in accordance with the International Standard ISO/IEC 17020:2012 - Conformity assessment – Requirements for the operation of various types of bodies performing inspection in line with our accreditation with UKAS as an Inspection Body (No 8831). The Quality Review Service closed on 31st July 2021, UKAS have asked that the accreditation symbol now be removed.

The standards can be used until they reach their expiry date – October 2021.

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Whilst the Quality Review Service has taken reasonable steps to ensure that these Quality Standards are fit for the purpose of reviewing the quality of services, this is not warranted, and the Quality Review Service will not have any liability to the service provider, service commissioner or any other person in the event that the Quality Standards are not fit for this purpose. The provision of services in accordance with these Standards does not guarantee that the service provider will comply with its legal obligations to any third party, including the proper discharge of any duty of care, in providing these services.

Review by: October 2021 at the latest

Version No	Date	Change from previous version
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. <ul style="list-style-type: none"> • Minor amendments: • Wording of QS HN-199 • Change of term to 'Non-Transfusion Dependent Thalassaemia (nTDT)' QS-HN 510 and QS HY-502 • QS-HN-703 updated • Evidence for compliance for meeting Trans Cranial Doppler U/S QS
V4.1	04.05.20	Re formatted with QRS Brand Amended SHC to SHT to reflect the terminology agreed for use during the 2019 -2020 review programme
V4.2	23.11.20	QRS Contact details amended. Added in addition to CQC that other regulatory frameworks are in use in the devolved nations. QS HN-601 amended to included 'were not brought' (children) and include 'k' use of systems and governance arrangements for virtual consultations
V4.3	31.07.21	UKAS logo removal

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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*' (2nd 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.

Aims of the Quality Standards

The Quality Standards aim to improve the quality of the health services for people with Haemoglobin Disorders 'pathway' and to help answer the question: "At each point on the pathway, how will I know that national guidance and best practice have been implemented?" The Quality Standards are suitable for use in self-assessment, monitoring by commissioners and providers, and peer review visits. They describe what services should be aiming

to provide and providers and commissioners should be moving towards meeting all applicable Quality Standards within the next two to five years. **Error! Reference source not found.** lists the references sources on which the Quality Standards are based.

Through use of the Quality Standards we hope that:

- a. The local community, service users and carers will know more about the services they can expect.
- b. Commissioners will be supported in assessing and meeting the needs of their population, improving health and reducing health inequalities, and will have better service specifications.
- c. Service providers and commissioners will work together to improve service quality.
- d. Service providers and commissioners will have external assurance of the quality of local services.
- e. Reviewers will learn from taking part in review visits.
- f. Good practice will be shared.
- g. Service providers and commissioners will have better information to give to the Care Quality Commission, NHS England and NHS Improvement. The devolved nations may have different regulatory frameworks in place but these QS can still be used with these frameworks to provide assurance to commissioners of services.

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:

SHT	Specialist Haemoglobinopathy Team
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 QRS 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.

Latest versions of QRS Quality Standards are available to on the QRS website www.qualityreviewservicewm.nhs.uk

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 the columns B-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. The devolved nations may have different regulatory frameworks in place but these QS can still be mapped to other frameworks to provide additional assurance to commissioners of services.

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

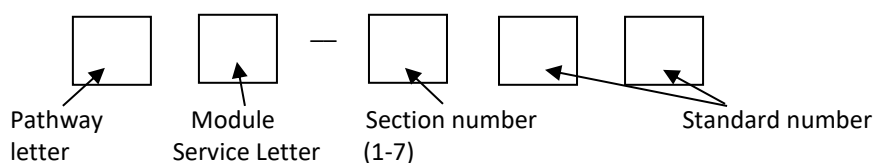
- If the tabs at the bottom of the spreadsheet do not appear, please minimise the spreadsheet and then maximise it again and the tabs should be there.
- 'Alt' and 'Enter' (together) allows you to put a new line within an Excel cell.

The PDF version includes appendices 1 to 5 which are not included in the Excel version.

Structure of the Quality Standards

QRS Quality Standards Reference Structure

QRS Quality Standard reference numbers have the following structure:



Each Standard is structured as follows:

<p>Reference Number (Ref)</p>	<p>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).</p> <p>The reference column also includes a guide to how the Standard will be reviewed:</p> <table border="1" data-bbox="612 1010 1214 1429"> <tr> <td>BI</td> <td>Background information</td> </tr> <tr> <td>Visit</td> <td>Visiting facilities</td> </tr> <tr> <td>MP&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										
<p>Quality Standard (QS)</p>	<p>This describes the quality that services are expected to provide.</p>										
<p>Notes</p>	<p><i>The notes give more detail about either the interpretation or the applicability of the Standard.</i></p>										

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.

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.

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 qrs@nhs.net

More information about QRS and its Quality Standards and reviews is available at www.qualityreview servicewm.nhs.uk

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Specialist services for people with Haemoglobin Disorders

Ref	Standard					
<h3 style="color: #00A68F;">Support for Service Users and their Carers</h3>						
<p>HN-101</p> <p>All</p> <table border="1" data-bbox="209 528 292 703"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Haemoglobin Disorder Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: <ol style="list-style-type: none"> i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HN-199) <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 1424 292 1599"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Information about Haemoglobin Disorders</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> a. A description of their condition (SC or T), how it might affect them and treatment available b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: <ol style="list-style-type: none"> i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. As QS HN-101. 2. Information may be given at different stages of the patient pathway.
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Ref	Standard					
<p>HN-103</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&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Care Plan</p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed <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"> 1. Care plans may be in the form of clinic letters or patient-held records. 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.
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<p>HN-104</p> <p>All</p> <table border="1" data-bbox="209 875 292 1055"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Information for Primary Health Care Team</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"> a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on: <ol style="list-style-type: none"> i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs) ii. Immunisations iii. Contraception and sexual health d. Indications and arrangements for seeking advice from the specialist service <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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<p>HN-105</p> <p>SHC</p> <table border="1" data-bbox="209 1402 292 1581"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)</p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated <p><i>Note:</i></p> <p><i>As QS HN-101.</i></p>
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HN-106 All <table border="1" data-bbox="209 315 292 495"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>School Care Plan (Children’s Services Only)</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"> School attended Medication, including arrangements for giving / supervising medication by school staff What to do in an emergency whilst in school Arrangements for liaison with the school Specific health or education need (if any) <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>This QS is not applicable to services for adults.</i> <i>‘School’ refers to nursery, school or college. This QS is applicable to all children and young people in full-time education.</i>
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HN-194 All <table border="1" data-bbox="209 768 292 947"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Environment</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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HN-195 SHC <table border="1" data-bbox="209 1104 292 1283"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Transition to Adult Services</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"> The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services A named coordinator for the transfer of care A preparation period prior to transfer Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>As QS HN-101</i> <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>
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<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&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Involving Patients and Carers</p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> Mechanisms for receiving feedback from patients and carers An annual patient survey (or equivalent) Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service Examples of changes made as a result of feedback and involvement of patients and carers <p><i>Notes:</i></p> <ol style="list-style-type: none"> The arrangements may be part of Trust-wide mechanisms so long as issues relating to haemoglobin disorder services can be identified. It is desirable that paediatric and adult services collaborate on involving young people and obtaining feedback on transition arrangements. A validated tool for collecting views of patients may be used for compliance with 'b' A 10% response rate for annual patient surveys is the minimum expected for compliance with this QS.
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<h2 style="color: #00A651;">Staffing</h2>						
<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&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Lead Consultant</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"> 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. '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). The lead consultant for services for children and young people may be a paediatrician or a paediatric haematologist. 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.
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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&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Lead Nurse</p> <p>A lead nurse should be available with:</p> <ol style="list-style-type: none"> Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders Responsibility for liaison with other services within the network Competences in caring for people with haemoglobin disorders Competences in the care of children and young people (children's services only) <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"> 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. 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. RCN competences for nurses caring for people with haemoglobin disorders are available at www.rcn.org.uk/professional-development/publications/pub-003874
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<p>HN-203</p> <p>All</p> <table border="1" data-bbox="209 315 292 490"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Medical Staffing and Competences</p> <p>The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <p>All services:</p> <ol style="list-style-type: none"> a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care <p>SHCs only:</p> <ol style="list-style-type: none"> c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders <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"> 1. <i>'Caring for haemoglobinopathy patients: Report of a national workforce survey.'</i> (2015), UK Forum on Haemoglobin Disorders, gives guidance on consultant staffing levels, which should be reflected in job plans, in particular: "For calculating consultant requirements it is suggested that consultant PAs are allocated as follows: <ol style="list-style-type: none"> a. 0.25PA CPD per consultant b. 1.5 PA for every 50 patients for direct clinical duties* made up as: <ol style="list-style-type: none"> i. Clinics including specialist annual review (2.0 hours/week) ii. Ward rounds (1.5 hours/week) iii. Day unit attendance and ad hoc consultations, on call (1.0 hour/week) iv. Clinical administration and MDT meetings (1.5 hours/week) c. 0.25 PA for every 50 patients for supporting activities- NHR and data collection, audit, teaching, patient liaison, network participation) d. 1PA for geographical area clinical lead e. Additional PAs as required (e.g. for specialist training, laboratory work, research, outreach clinics). <p><i>*Some of these duties may be delegated to clinical nurse specialist or specialty doctors, with the appropriate training: this must be recognised in their job plans."</i></p> 2. <i>'c' may be achieved through network arrangements, through collaboration between paediatric and adult services or through collaboration between Specialist Centres.</i> 3. <i>Opportunities for doctors in training should include clinic attendance and care of in-patients. In low prevalence areas this should include the opportunity to spend time in a Specialist Centre in a high prevalence area.</i> 4. <i>Competences should be maintained through appropriate CPD. Documentation of CPD undertaken is not required but reviewers will ask about this.</i>
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<p>HN-204</p> <p>All</p> <table border="1" data-bbox="209 315 292 490"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Nurse Staffing and Competences</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"> Clinical nurse specialist/s with responsibility for the acute service Clinical nurse specialist/s with responsibility for the community service Ward-based nursing staff Day unit (or equivalent) nursing staff Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion <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"> <i>Clinical nurse specialist roles for acute and community services may be combined, especially in low prevalence areas.</i> <i>This QS covers nursing staff on wards to which people with haemoglobin disorders are usually admitted.</i> <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> <i>RCN competences for nurses caring for people with haemoglobin disorders are available at www.rcn.org.uk/professional-development/publications/pub-003874</i> <i>Competences should be maintained through appropriate CPD. Documentation of CPD undertaken is not required but reviewers will ask about this.</i> <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>
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<p>HN-205</p> <p>All</p> <table border="1" data-bbox="209 1323 292 1498"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Psychology Staffing and Competences</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"> An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care Time for input to the service’s multi-disciplinary discussions and governance activities Provision of, or arrangements for liaison with and referral to, neuro-psychology <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"> <i>This QS is not specific about the arrangements for cover for absences and different arrangements will be appropriate in different sized services.</i> <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>
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HN-206 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Training Plan</p> <p>A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>This QS applies to nursing and psychology staff (QS HN-204 and HN-205) and any non-consultant, non-training medical staff (QS HN-203).</i> <i>The training plan should cover competences in the care of people with haemoglobin disorders. The plan may also cover mandatory training but generic mandatory training only is not sufficient for compliance with this QS. Reviewers may comment on aspects of mandatory training that are relevant to the care of people with haemoglobin disorders, including safeguarding.</i> <i>This QS is about the needs of the service and cannot be met solely by individual staff appraisals and personal development reviews (PDRs), details of which are not required. Reviewers may request information about specific aspects of relevance to the service, in particular, where a therapeutic intervention or activity is undertaken rarely and/or where competence may not be maintained by the individual's usual clinical practice.</i>
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HN-207 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)</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"> <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> <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>
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HN-299 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>The amount of administrative, clerical and data collection support is not defined. Clinical staff should not, however, be spending unreasonable amounts of time which could be used for clinical work on administrative tasks and data entry.</i> <i>Administrative, clerical and data collection support should be available for Trans-Cranial Doppler ultrasound scans as well as for other aspects of the service.</i>
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Support Services						
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<p>HN-302</p> <p>All</p> <table border="1" data-bbox="209 1140 292 1319"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Emergency Department – Staff Competences</p> <p>Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>This QS applies to Emergency Departments normally attended by people with haemoglobin disorders.</i> <i>Documentation of training undertaken and discussion of audits of compliance with NICE Clinical Guideline on the management of acute pain could be used to demonstrate compliance with this QS.</i>
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<p>HN-303</p> <p>SHC</p> <table border="1" data-bbox="209 1514 292 1693"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Specialist On-site Support</p> <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"> Manual exchange transfusion (24/7) Erythrocytapheresis Acute pain team including specialist monitoring of patients with complex analgesia needs High dependency care, including non-invasive ventilation Level 2 and 3 critical care <p><i>Note:</i></p> <p><i>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.</i></p>
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<p>HN-304</p> <p>SHC</p> <table border="1" data-bbox="209 315 292 490"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Specialist Services - Network</p> <p>Access to the following specialist staff and services with an appropriate level of specialist expertise in the care of people with haemoglobin disorders should be available:</p> <ol style="list-style-type: none"> a. Pulmonary hypertension team (adults) b. Consultant obstetrician with an interest in care of people with haemoglobin disorders and specialist high risk anaesthetics (adults) c. Respiratory physician with interest in acute/chronic sickle lung disease and obstructive sleep apnoea (adults & children) d. Fertility, including pre-implantation genetic diagnosis and sperm storage (adults) e. Consultant cardiologist with interest in sickle cardiomyopathy, iron overload related heart disease (adults) f. Consultant endocrinologist with interest in thalassaemia related endocrinopathy and osteoporosis (adults) g. Consultant paediatric endocrinologist with interest in growth problems related to haemoglobinopathies and thalassaemia related endocrinopathy (children) h. Hepatobiliary team with an interest in sickle hepatopathy, viral liver disease, iron overload-related liver disease (adults & children) i. Consultant neurologist and neurosurgeon with an interest in sickle vasculopathy (adults & children) j. Hyperacute stroke service (adults) k. Consultant ophthalmologist with an expertise in sickle retinopathy and chelation related eye disease (adults & children) l. Consultant nephrologist with expertise in sickle nephropathy (adults & children) m. Consultant urologist with expertise in managing priapism and erectile dysfunction (adults & children) n. Orthopaedic service with expertise in managing sickle and thalassaemia related bone disease (adults & children) o. Specialist imaging, including <ol style="list-style-type: none"> i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) p. Bone marrow transplantation services (children only) q. Physiotherapy services (in patient and community based) r. Interventional and neuroradiology for neurovascular complications <p><i>Note:</i> <i>The specialist services to which patients are referred may be within or outside the network. The network should agree the services to which patients are referred and the indications for referral (QS HY-502).</i></p>
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<p>HN-305</p> <p>All</p> <table border="1" data-bbox="209 1738 292 1912"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Laboratory Services</p> <p>UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.</p>
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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&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	Transition Guidelines Guidelines on transition to adult care should be in use covering at least: <ol style="list-style-type: none"> 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. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams <p><i>Notes:</i></p> <ol style="list-style-type: none"> 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**). 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.
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HN-502 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&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	Monitoring Protocols Protocols should be in use covering the monitoring expected at: <ol style="list-style-type: none"> a. First out-patient appointment (SHC only) b. Routine monitoring c. Annual review (SHC & any LHTs to which annual reviews are delegated) Protocols should cover both clinical practice and information for patients and families. <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. As QS HN-501 note 1 2. First out-patient appointment protocols should be used for newly diagnosed patients and for those who have recently moved into the area, including from outside the UK. Initial prescriptions for penicillin should normally be provided by the specialist centre with GPs asked to issue subsequent prescriptions. Babies moving to the UK aged under one year should be referred for screening.
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HN-504 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 style="background-color: #4b8cbe; color: white;"><td style="text-align: center;">MP&S</td></tr> <tr style="background-color: #4b8cbe; color: white;"><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4b8cbe; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Transfusion Guidelines</p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> Indications for: <ol style="list-style-type: none"> emergency and regular transfusion use of simple or exchange transfusion offering access to automated exchange transfusion to patients on long-term transfusions Protocol for carrying out a manual and automated exchange transfusion Investigations and vaccinations prior to first transfusion Recommended number of cannulation attempts <p><i>Notes:</i></p> <ol style="list-style-type: none"> As QS HN-501 note 1 The Standards documents (see Appendix 1, references 10, 12 and 13) recommend that no more than three cannulation attempts should be made by one individual. If automated exchange transfusions are provided by another provider then this aspect of 'b' is not applicable.
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HN-505 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 style="background-color: #4b8cbe; color: white;"><td style="text-align: center;">MP&S</td></tr> <tr style="background-color: #4b8cbe; color: white;"><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #4b8cbe; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Chelation Therapy</p> <p>Guidelines on chelation therapy should be in use covering:</p> <ol style="list-style-type: none"> Indications for chelation therapy Choice of chelation drug/s, dosage and dosage adjustment Monitoring of haemoglobin levels prior to transfusion Management and monitoring of iron overload, including management of chelator side effects Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible. <p><i>Notes:</i></p> <ol style="list-style-type: none"> As QS HN-501 note 1 Starting chelation, and most alterations in treatment regimen, should be discussed with the SHC before change by the LHT. Indications for chelation therapy should be based on NHS England guidelines (2016).
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<p>HN-507</p> <p>All</p> <table border="1" data-bbox="209 1064 292 1238"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Specialist Management Guidelines</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"> During anaesthesia and surgery Who are pregnant Receiving hydroxycarbamide therapy <p><i>Notes:</i></p> <ol style="list-style-type: none"> As QS HN-501 note 1 Guidelines should be specific about differences between the care of sickle cell disease and thalassaemia and should be based on network-agreed guidelines.
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<p>HN-508</p> <p>All</p> <table border="1" data-bbox="209 1442 292 1617"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Clinical Guidelines: Chronic complications</p> <p>Guidelines on the management of chronic complications should be in use covering at least:</p> <ol style="list-style-type: none"> Renal disease Orthopaedic problems Retinopathy Cardiological complications / pulmonary hypertension Chronic respiratory disease Endocrinopathies Neurological complications Chronic pain Liver disease Growth delay / delayed puberty (children only) Enuresis (children only) <p><i>Notes:</i></p> <ol style="list-style-type: none"> As QS HN-501 note 1 Guidelines should be based on NICE guidance or other evidence of effectiveness and on network agreed guidelines (HY-502).
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HN-510 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Non-Transfusion Dependent Thalassaemia (nTDT) Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: <ol style="list-style-type: none"> Indications for transfusion Monitoring iron loading Indications for splenectomy <i>Notes:</i> <ol style="list-style-type: none"> As QS HN-501 note 1 Indications for transfusion may be part of the transfusion guidelines in QS HN-504 Indications for monitoring iron loading may be part of the guidelines on chelation therapy HN -505
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Service Organisation and Liaison with Other Services						
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<p>HN-602</p> <p>All</p> <table border="1" data-bbox="209 1435 292 1610"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Multi-Disciplinary Meetings</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"> 1. Support services (QS HN-301) should be able to attend multi-disciplinary team meetings when required. 2. 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.
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<p>HN-603</p> <p>SHC</p> <table border="1" data-bbox="209 1888 292 2063"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Delegation of Annual Reviews</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"> a. Monitoring protocols (QS HN-502) b. LHT management and referral guidelines (QS HN-503) c. National Haemoglobinopathy Registry data collection (QS HN-701)
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Ref	Standard					
HN-604 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Out of Hours Elective Care Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. <i>Note:</i> <i>This QS is not specific about the extent of out of hours elective care which should be available. This will depend on the size of the service but should ensure that, as far as possible, the impact of regular transfusion on patients' education and employment is minimised.</i>
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HN-605 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Service Level Agreement with Community Services A service level agreement for support from community services should be in place covering, at least: <ol style="list-style-type: none"> Role of community service in the care of patients with haemoglobin disorders Two-way exchange of information between hospital and community services. <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"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only) A Standard Operating Procedure for Trans-Cranial Doppler ultrasound should be in use covering at least: <ol style="list-style-type: none"> Trans-Cranial Doppler modality used Identification of ultrasound equipment and maintenance arrangements Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-207) 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 Arrangements for recording and storing images and ensuring availability of images for subsequent review Reporting format Arrangements for documentation and communication of results Internal systems to assure quality, accuracy and verification of results <i>Notes:</i> <ol style="list-style-type: none"> <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> <i>Guidelines should be specific about supervision of staff in training.</i> <i>Internal quality assurance systems may include double-reading of a sample of results.</i>
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HN-607 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Network Review and Learning Meetings 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&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Neonatal Screening Programme Review Meetings <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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<h2 style="color: #0070C0;">Governance</h2>						
HN-701 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	National Haemoglobinopathy Registry <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"> <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> <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>
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HN-702 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Activity Data <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances Length of in-patient stays Re-admission rate 'Did not attend' rate for out-patient appointments
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HN-703 SHC <table border="1" data-bbox="209 315 292 490"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Quality Dashboard</p> <p>The service should monitor Quality Dashboard data including the number and percentage of:</p> <ol style="list-style-type: none"> Adverse events reported on the NHR for which a mortality or serious case review has taken place Children who have had Trans-Cranial Doppler screening undertaken within national guidelines Patients given pain relief within half an hour of presentation with sickle crisis Patients with possible sickle disorders identified by neonatal screening who have been entered on a care pathway Eligible children beginning penicillin at or before three months of age Patients registered on the National Haemoglobinopathy Registry who had an annual review undertaken within the last year Patients on long-term transfusion who received cardiac MRI, and the proportion of those receiving a cardiac MRI who achieved a figure of less than 20ms Eligible patients with sickle cell disease who received an MRI for liver iron, and the proportion of those who received an MRI for liver iron who achieved more than 7 mg/gm/DW (sickle cell and thalassaemia separately) <p><i>Notes:</i></p> <ol style="list-style-type: none"> This QS is based on the 2018/19 Quality Dashboard available at: https://www.england.nhs.uk/wp-content/uploads/2018/03/haemoglobinopathy-metric-definitions-2018-19.pdf Later versions of the Dashboard should be used when available. Further details of data definitions and time periods are given in the published Dashboard This QS covers SHC patients, QS HY-701 covers data collection for all patients in the network.
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HN-704 SHC <table border="1" data-bbox="209 1137 292 1312"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Other Quality Data</p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> Proportion of children who have been offered treatment following Trans-Cranial Doppler Screening
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HN-705 All <table border="1" data-bbox="209 1397 292 1572"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Other Audits</p> <p>Clinical audits covering the following areas should have been undertaken within the last two years:</p> <ol style="list-style-type: none"> Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies Whether all eligible patients on long term transfusion have been offered automated exchange transfusion Waiting times for elective: <ol style="list-style-type: none"> Phlebotomy Cannulation Setting up of the blood transfusion (for pre-ordered blood) <p><i>Note:</i> Evidence of audit should include 'closing the loop'.</p>
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HN-706 All <table border="1" data-bbox="209 1883 292 2058"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Network Audits</p> <p>The service should participate in agreed network-wide audits.</p> <p><i>Note:</i> Evidence of completion of planned audits, including 'closing the loop' is appropriate documentary evidence of compliance with this QS.</p>
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Ref	Standard					
HN-707 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Research</p> <p>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.</p> <p><i>Note:</i> <i>A list of trials participated in in the last three years and the number of patients recruited into trials is appropriate documentary evidence of compliance with this QS.</i></p>
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HN-708 SHC <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Trans-Cranial Doppler Quality Assurance (Children's Services Only)</p> <p>The service should monitor and review at least annually:</p> <ol style="list-style-type: none"> Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-207) Results of internal quality assurance systems (QS HN-606) Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) <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&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Review and Learning</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"> Review of any patient with a serious adverse event or who died Review of any patients requiring admission to a critical care facility 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) <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>These arrangements should include feedback to operational staff and should link with Trust-wide (or equivalent) governance arrangements.</i> <i>As QS HN-701.</i>
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HN-799 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Document Control</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>
BI						
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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					
Support for Service Users and their Carers						
HY-199 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Involving Patients and Carers <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p>
BI						
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MP&S						
CNR						
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Staffing						
HY-201 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Network Leads <p>The network should have a nominated:</p> <ol style="list-style-type: none"> Lead consultant and deputy Lead specialist nurse for acute care Lead specialist nurse for community services Lead manager Lead for service improvement Lead for audit Commissioner <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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HY-202 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	Education and Training <p>The network should have agreed a programme of education and training to help services achieve compliance with QS HN-206.</p>
BI						
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MP&S						
CNR						
Doc						

Guidelines and Protocols

HY-501

BI
Visit
MP&S
CNR
Doc

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
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MP&S
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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>HY-701</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Ongoing Monitoring</p> <p>The network should monitor on a regular basis:</p> <ol style="list-style-type: none"> Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year Network-wide activity levels (HN-702)
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<p>HY-702</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Audit</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>
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<p>HY-703</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Research</p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> A policy on access to research relating to the care of patients with haemoglobin disorders A list of research trials available to all patients within the network.
BI						
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<p>HY-798</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Network Review and Learning</p> <p>The SHC should meet at least twice a year with its referring LHT teams to:</p> <ol style="list-style-type: none"> Identify any changes needed to network-wide policies, procedures and guidelines Review results of audits undertaken and agree action plans Review and agree learning from any positive feedback or complaints involving liaison between teams Review and agree learning from any critical incidents or ‘near misses’, including those involving liaison between teams Consider the content of future training and awareness programmes (QS HY-202)
BI						
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MP&S						
CNR						
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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>Commissioning of Services</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"> Designated SHC/s for the care of people with sickle cell disease Designated SHC/s for the care of adults with thalassaemia Any agreements for delegation of annual reviews to LHTs for care of people with sickle cell disease or thalassaemia Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia Community care providers
HZ-701 BI Visit MP&S CNR Doc	<p>Clinical Quality Review Meetings</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"> National Haemoglobinopathy Registry data collection (QS HN-701) Quality Dashboard (QS HN-703) <p><i>Notes:</i></p> <ol style="list-style-type: none"> 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. In networks with more than one SHC, or overlapping networks, Clinical Quality Review Meetings may be combined.

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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 https://www.sicklecellsociety.org/resources/	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 www.leadershipacademy.nhs.uk/	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 nd Edition)	9.
2016	United Kingdom Thalassaemia Society	Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (3 rd 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 nd Edition.	23.
2008	NCEPOD	A sickle crisis? A report of the National Confidential Enquiry in Patient Outcome and Death report	24.

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
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HN-195	2,6,7,10,12,14,21,23	HN-505	7,8,10,12,14,18	HN-707	7,9,12,14
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 QRS 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?

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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-501	6, 8.2, 9		x	x	x			x			x				x			x											
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																
HN-505				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	
HN-703	3.2, 4, 7, 8,11					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-704	3.2, 4, 7, 8,11					x	x	x	x													x		x	x	x	x	x	
HN-705	3.2, 4, 7, 8,11					x	x	x	x															x	x	x	x	x	
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	
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					
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	
Advocacy	Advocacy means to speak up for someone. It is about making things change because people's voices are heard and listened to. It is 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.
BI	Background information to review team.
Carer	Throughout the Quality Standards the term 'carer' applies to both family carers and paid carers or support workers.
CCG	Clinical Commissioning Group.
Commissioner	A commissioner decides how NHS and / or social care resources are spent, with the aim of improving health, reducing inequalities, and enhancing patient experience.
CNR	Case note review or clinical observation.
CPA	Clinical Pathology Accreditation
CPD	Continuing Professional Development
CQC	The Care Quality Commission is the independent regulator of health and social care in England.
DH	Department of Health.
DNA studies	Genetic studies for Deoxyribonucleic acid to give genealogical information on a patient's condition
Doc	Documentation should be available. Documentation may be in the form of a website or other social media.
ENT	Ear Nose and Throat
GP	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.
HbSB	Sickle cell–haemoglobin C
HbSS	Sickle cell–haemoglobin S
HealthWatch	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.
LBR	Learning beyond registration.
LHT	Local Haemoglobinopathy Teams (or Linked Providers)
mg/gm/DW	Calculation formula –milligram/gram/dry weight
MHRA	Medicines and Healthcare Products Regulatory Agency
MP&S	Meeting patients, carers and staff.
MRI	Magnetic resonance imaging
NEQAS	National External Quality Assessment Service
NHR	National Haemoglobinopathy Registry
NICE	National Institute for Health and Care Excellence.
NHS England and NHS Improvement	These two organisations work together and are at the head of the NHS in England. They set and drive delivery of NHS priorities that respond to the Government's strategic goals for health and care.
NQAS	National Quality Assurance Scheme
NVQ	National Vocational Qualification.
PA	Programmed Activity
PALS	Patient Advice and Liaison Service

Glossary of terms and abbreviations

PDR	Performance Development Review.
PICU	Paediatric Intensive Care Unit
Provider	A health or social care organisation which provides services to patients.
QRS	Quality Review Service
QS	Quality Standard.
RCN	Royal College of Nursing
SC	Sickle Cell
School	Nursery, school or college
Service provider	See 'Provider'.
Service commissioner	See 'Commissioner'.
SHC	Specialist Haemoglobinopathy Centre
T	Thalassaemia
TCD	Trans-Cranial Doppler
Trust	A NHS Trust, NHS Foundation Trust or other organisation with management responsibility for the service.
UKAS	UK Accreditation Service
WTE	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	
Background information	This means that the information should be included in the background report or self-assessment.
Visiting facilities	Reviewers will look for the information while they are visiting the service.
Meeting patients, carers and staff	These Standards will be discussed with patient, carers and /or staff as appropriate.
Case note review or clinical observation	A few Quality Standards require reviewers to look at case notes or other clinical information.
Documentation	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	Haemoglobin Disorder Service Information		X	X		X	Service information
HN-102	Information about Haemoglobin Disorders		X	X		X	Condition specific information
HN-103	Care Plan			X	X	X	Example of care plan or template
HN-104	Information for Primary Health Care Team			X	X	X	Primary Care team information
HN-105	Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)		X	X		X	TCD information
HN-106	School Care Plan (Children's Services Only)			X		X	Example of school care plan or template
HN-194	Environment		X	X			
HN-195	Transition to Adult Services		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	Involving Patients and Carers			X		X	Examples of methods of receiving feedback. Examples of changes made as a result of feedback
HN-201	Lead Consultant	X					
HN-202	Lead Nurse	X		X			
HN-203	Medical Staffing and Competences			X		X	Competence framework describing the competences expected for roles within the service.
HN-204	Nurse Staffing and Competences			X		X	Competence framework describing the competences expected for roles within the service.
HN-205	Psychology Staffing and Competences			X		X	Competence framework describing the competences expected for roles within the service.
HN-206	Training Plan			X		X	Training plan including achievement of competences expected for roles within the service
HN-207	Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)			X		X	Monitoring records and log books for individual practitioners
HN-299	Administrative, Clerical and Data Collection Support	X					
HN-301	Support Services	X		X			
HN-302	Emergency Department – Staff Competences	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	Specialist On-site Support	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	Specialist Services – Network	X		X			
HN-305	Laboratory Services			X			
HN-401	Facilities and Equipment		X				
HN-501	Transition Guidelines			X	X	X	Guidelines
HN-502	Monitoring Protocols			X	X	X	Examples of checklists
HN-503	Clinical Guidelines: LHT Management and Referral			X	X	X	Monitoring and management guidelines
HN-504	Transfusion Guidelines			X	X	X	Guidelines
HN-505	Chelation Therapy			X	X	X	Clinical guidelines
HN-506	Clinical Guidelines: Acute Complications			X	X	X	Clinical guidelines
HN-507	Specialist Management Guidelines			X	X	X	Clinical guidelines
HN-508	Clinical Guidelines: Chronic Complications			X	X	X	Clinical guidelines
HN-509	Referral for Consideration of Bone Marrow Transplantation (Children’s Services Only)					X	Referral guidelines
HN-510	Non-Transfusion Dependent Thalassaemia (nTDT)					X	Clinical guidelines
HN-599	Clinical Guideline Availability			X			
HN-601	Service Organisation					X	Service organisation policy
HN-602	Multi-Disciplinary Meetings					X	Minutes of meetings held within the service. Meeting records showing percentage of meetings attended by staff.
HN-603	Delegation of Annual Reviews			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	Out of Hours Elective Care			X			
HN-605	Service Level Agreement with Community Services					X	Service level agreement
HN-606	Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)					X	Trans-cranial doppler ultrasound guidelines
HN-607	Network Review and Learning Meetings					X	Minutes of meetings
HN-608	Neonatal Screening Programme Review Meetings					X	Minutes of meetings
HN-701	National Haemoglobinopathy Registry			X		X	National Haemoglobinopathy Registry data reports
HN-702	Activity Data	X				X	Examples of data showing compliance with QS
HN-703	Quality Dashboard			X		X	Examples of data showing compliance with QS
HN-704	Other Quality Data			X		X	Examples of data showing compliance with QS
HN-705	Other Audits					X	Audit programme or plan Examples of completed audits, action plans and monitoring, including 'closing the loop'.
HN-706	Network Audits			X		X	Evidence of completion of planned audits, including 'closing the loop'
HN-707	Research	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	Trans-Cranial Doppler Quality Assurance (Children's Services Only)					X	Evidence of quality monitoring and log books for individual practitioners
HN-798	Review and Learning			X		X	Documentation depends on local arrangements, for example, minutes of review and learning meetings held within the service.
HN-799	Document Control					X	Compliance determined from other documentation presented
HY-199	Involving Patients and Carers			X		X	Examples of methods of receiving feedback. Examples of changes made as a result of feedback
HY-201	Network Leads	X					
HY-202	Education and Training			X		X	Education and training programme
HY-501	Transition Guidelines			X	X	X	Guidelines
HY-502	Clinical Guidelines			X	X	X	Clinical guidelines
HY-601	Network Multi-Disciplinary Discussion			X		X	Minutes of meetings
HY-701	Ongoing Monitoring			X		X	Quality monitoring report
HY-702	Audit			X		X	Audit programme
HY-703	Research			X		X	Research policy
HY-798	Network Review and Learning			X		X	Documentation depends on local arrangements, for example, minutes of review and learning meetings held within the network.
HZ-601	Commissioning of Services			X		X	Service commissioning plans
HZ-701	Clinical Quality Review Meetings					X	Notes of meetings

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