

**Adult Standards -100s**

QS Ref. Number	V5 Quality Standards (Adults)	V5 Notes (Adults)
HA-101	<p><b>Haemoglobin Disorder Service Information</b>                      Written information should be offered to patients and their carers, and should be easily available within patient areas, covering at least:</p> <ul style="list-style-type: none"> <li>a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services</li> <li>b. Clinic times and how to change an appointment</li> <li>c. Ward usually admitted to and its visiting times</li> <li>d. Staff of the service</li> <li>e. Community services and their contact numbers</li> <li>f. Relevant national organisations and local support groups</li> <li>g. Where to go in an emergency</li> <li>h. How to:                             <ul style="list-style-type: none"> <li>i. Contact the service for help and advice, including out of hours</li> <li>ii. Access social services</li> <li>iii. Access benefits and immigration advice</li> <li>iv. Contact interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)</li> <li>v. Give feedback on the service, including how to make a complaint</li> <li>vi. Get involved in improving services (QS HA-199)</li> </ul> </li> </ul>	<p>1. Information should be written in clear, plain English and should be available in formats and languages appropriate to the needs of patients and their carers. Reviewers will expect to see information in languages other than English where a significant group of patients may not speak English.</p>
HA-102	<p><b>Information about Haemoglobin Disorders</b>                      Patients and their carers should be offered written information, or written guidance on where to access information, covering at least:</p> <ul style="list-style-type: none"> <li>a. A description of their condition (SC or T), how it might affect them and treatment available</li> <li>b. Inheritance of the condition and implications for fertility</li> <li>c. Problems, symptoms and signs for which emergency advice should be sought</li> <li>d. How to manage pain at home (SC only)</li> <li>e. Transfusion and iron chelation</li> <li>f. Possible complications</li> <li>g. Health promotion, including:                             <ul style="list-style-type: none"> <li>i. Travel advice</li> <li>ii. Vaccination advice</li> </ul> </li> <li>h. National Haemoglobinopathy Registry, its purpose and benefits</li> <li>i. Self-administration of medications and</li> </ul>	<p>1. As QS HA-101.                      2. Providing links to national or other websites which provide more detailed information is sufficient for compliance with this QS. Information may be given at different stages of the patient pathway.                      3. Information on inheritance and fertility should be available for males as well as females.</p>

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HA-103	<p><b>Care Plan</b>All patients should be offered:</p> <p>a. An individual care plan or written summary of their annual review including:</p> <ul style="list-style-type: none"> <li>i. Information about their condition</li> <li>ii. Planned acute and long-term management of their condition, including medication</li> <li>iii. Named contact for queries and advice</li> </ul> <p>b. A permanent record of consultations at which changes to their care are discussed</p> <p>The care plan and details of any changes should be copied to the patients' GP and their local team consultant (if applicable)</p>	<p>Care plans may be in the form of clinic letters, patient-held records or other formats. For compliance with this QS reviewers will expect to see the patient's version, GP communication and the clinical record (which may be the same if patient letters are copied to the GP).</p>
HA-104	<p><b>What to Do in an Emergency?</b></p> <p>All patients should be offered information about what to do in an emergency covering at least:</p> <ul style="list-style-type: none"> <li>a. Where to go in an emergency</li> <li>b. Pain relief and baseline oxygen level, if abnormal (SC only)</li> </ul>	<ul style="list-style-type: none"> <li>1. As QS HA-103.</li> <li>2. Information on what to do in an emergency may be part of the Care Plan (QS HA-103), may be combined with other information or may be separate.</li> </ul>
HA-105	<p><b>Information for Primary Health Care Team</b></p> <p>Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and:</p> <ul style="list-style-type: none"> <li>a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)</li> <li>b. Side effects of medication, including chelator agents [SC and T]</li> <li>c. Guidance for GPs on: <ul style="list-style-type: none"> <li>i. Immunisations</li> <li>ii. Contraception and sexual health</li> </ul> </li> <li>d. What to do in an emergency</li> <li>e. Indications and arrangements for seeking advice from the specialist service</li> </ul>	

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HA-194	<p><b>Environment and Facilities</b> 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.</p>	<ol style="list-style-type: none"> <li>1. Evidence of admissions of patients to other clinical areas may be used in determining compliance with this QS.</li> <li>2. Issues relating to the availability and maintenance of equipment may also be raised under this QS.</li> </ol>
HA-195	<p><b>Transition to Adult Services</b> Young people approaching the time when their care will transfer to adult services should be offered:</p> <ol style="list-style-type: none"> <li>a. Information and support on taking responsibility for their own care</li> <li>b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services</li> <li>c. A named coordinator for the transfer of care</li> <li>d. A preparation period prior to transfer</li> <li>e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards</li> <li>f. Advice for young people leaving home or studying away from home including:             <ol style="list-style-type: none"> <li>i. registering with a GP</li> <li>ii. how to access emergency and routine care</li> <li>iii. how to access support from their specialist service</li> <li>iv. communication with their new GP</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>1. This QS is normally applicable only to SHTs. If networks agree to transition directly to LHTs then this QS is applicable also to these teams. This QS applies to both adult and paediatric services as both need to be involved in the transfer of care.</li> <li>2. Additional information on transition to adult services and preparation for adult life is available from 'Ready Steady Go' and other similar transition programmes.</li> <li>3. Young people in full time education up to the age of 19 should have a 'school or college care plan' (QS HC-107) and this should include transition information if not covered elsewhere.</li> <li>3. Arrangements should comply with national guidance for Looked After Children - Preparing for Independence <a href="https://www.nice.org.uk/guidance/ph28">https://www.nice.org.uk/guidance/ph28</a></li> <li>4. Transition should cover all aspects of a young person's needs, including their psychosocial and emotional needs. Specialist services should be involved in transition planning for young people with more complex needs (eg. disability, mental health or chronic pain) to ensure that all aspects of their needs are taken in account.</li> </ol>
HA-197	<p><b>Gathering Patients' and Carers' Views</b>The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia</p>	<ol style="list-style-type: none"> <li>1. Survey questionnaires for use in this QS can be accessed on <a href="https://www.picker.org/tools-resources/toolkits/">https://www.picker.org/tools-resources/toolkits/</a></li> <li>2. A 10% response rate for patient surveys is the minimum expected for compliance with this QS.</li> <li>3. Discussion of responses and actions required is covered by QS HA-797.</li> </ol>
HA-198	<p><b>Network-wide Patient and Carer Involvement</b> The HCC should have mechanisms for involving patients and carers, including representation at HCC Business Meetings (QS HA-702).</p>	
HA-199	<p><b>Involving Patients and Carers</b> The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> <li>a. Mechanisms for receiving feedback</li> <li>b. Mechanisms for involving patients and their carers in:             <ol style="list-style-type: none"> <li>i. decisions about the organisation of the service</li> <li>ii. discussion of patient experience and clinical outcomes (QS HA-797)</li> </ol> </li> <li>c. Examples of changes made as a result of feedback and involvement</li> </ol>	<ol style="list-style-type: none"> <li>1. The arrangements may be part of Trust-wide mechanisms so long as issues relating to haemoglobin disorder services can be identified.</li> <li>2. It is desirable that paediatric and adult services collaborate on involving young people and obtaining feedback on transition arrangements.</li> </ol>

**Paediatric Standards -100's**

QS Ref. Number	V5 Quality Standards (Children)	V5 Notes (Children)
HC-101	<p><b>Haemoglobin Disorder Service Information</b> Written information should be offered to children, young people and their families, and should be easily available within patient areas, covering at least:</p> <ul style="list-style-type: none"> <li>a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services</li> <li>b. Clinic times and how to change an appointment</li> <li>c. Ward usually admitted to and its visiting times</li> <li>d. Staff of the service</li> <li>e. Community services and their contact numbers</li> <li>f. Relevant national organisations and local support groups</li> <li>g. Where to go in an emergency</li> <li>h. How to:                             <ul style="list-style-type: none"> <li>i. Contact the service for help and advice, including out of hours</li> <li>ii. Access social services</li> <li>iii. Access benefits and immigration advice</li> <li>iv. Contact interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)</li> <li>v. Give feedback on the service, including how to make a complaint</li> <li>vi. Get involved in improving services (QS HC-199)</li> </ul> </li> </ul>	<p>1. Information should be age-appropriate, written in clear, plain English and should be available in formats and languages appropriate to the needs of children, young people and their families. Information should meet the 'You're Welcome – Quality criteria for young people friendly health services', (DH, 2011). Reviewers will expect to see information in languages other than English where a significant group of patients may not speak English.</p> <p>2. Throughout the Quality Standards 'family' includes parents, siblings, grandparents, extended family members or others with carer responsibility. This includes the responsible social worker for children in the care of the Local Authority.</p>
HC-102	<p><b>Information about Haemoglobin Disorders</b> Children, young people and their families should be offered written information, or written guidance on where to access information, covering at least:</p> <ul style="list-style-type: none"> <li>a. A description of their condition (SC or T), how it might affect them and treatment available</li> <li>b. Inheritance of the condition and implications for fertility</li> <li>c. Problems, symptoms and signs for which emergency advice should be sought</li> <li>d. How to manage pain at home (SC only)</li> <li>e. Transfusion and iron chelation</li> <li>f. Trans-Cranial Doppler scanning</li> <li>g. Possible complications</li> <li>h. Health promotion, including:                             <ul style="list-style-type: none"> <li>i. Travel advice</li> <li>ii. Vaccination advice</li> </ul> </li> <li>i. National Haemoglobinopathy Registry, its purpose and benefits</li> <li>j. Parental or self-administration of medications and infusions</li> </ul>	<p>1. As QS HC-101.2. Providing links to national or other websites which provide more detailed information is sufficient for compliance with this QS. Information may be given at different stages of the patient pathway.</p> <p>3. Information on inheritance and fertility should be available for males as well as females.</p>

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<p>HC-103</p>	<p><b>Care Plan</b>  All patients should be offered:  a. An individual care plan or written summary of their annual review including:  i. Information about their condition  ii. Planned acute and long-term management of their condition, including medication  iii. Named contact for queries and advice  b. A permanent record of consultations at which changes to their care are discussed  The care plan and details of any changes should be copied to the patients' GP and their local team consultant (if applicable)</p>	<p>Care plans may be in the form of clinic letters, patient-held records or other formats. For compliance with this QS reviewers will expect to see the patient's version, GP communication and the clinical record (which may be the same if patient letters are copied to the GP).</p>
<p>HC-104</p>	<p><b>What to Do in an Emergency?</b>  All children and young people should be offered information about what to do in an emergency covering at least:  a. Where to go in an emergency  b. Pain relief and baseline oxygen level, if abnormal (SC only)</p>	<p>1. As QS HC-103.  2. Information on what to do in an emergency may be part of the Care Plan (QS HC-103), may be combined with other information or may be separate.</p>
<p>HC-105</p>	<p><b>Information for Primary Health Care Team</b>  Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and:  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:  i. Immunisations  ii. Contraception and sexual health (if appropriate)  d. What to do in an emergency  e. Indications and arrangements for seeking advice from the specialist service</p>	
<p>HC-106</p>	<p><b>Information about Trans-Cranial Doppler Ultrasound</b>  Written information should be offered to children, young people and their families covering:  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>	<p>As QS HC-101.</p>

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<p>HC-107</p>	<p><b>School or College Care Plan</b>  A School or College Care Plan should be agreed for each child or young person covering at least:</p> <ol style="list-style-type: none"> <li>School or college attended</li> <li>Medication, including arrangements for giving / supervising medication by school or college staff</li> <li>What to do in an emergency whilst in school or college</li> <li>Arrangements for liaison with the school or college</li> <li>Specific health or education need (if any)</li> </ol>	<p>'School' refers to nursery, school or college. This QS is applicable to all children and young people in full-time education and aged under 19.</p>
<p>HC-194</p>	<p><b>Environment and Facilities</b>  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 age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.</p>	<ol style="list-style-type: none"> <li>Evidence of admissions of patients to other clinical areas may be used in determining compliance with this QS.</li> <li>Issues relating to the availability and maintenance of equipment may also be raised under this QS.</li> </ol>
<p>HC-195</p>	<p><b>Transition to Adult Services</b>  Young people approaching the time when their care will transfer to adult services should be offered:</p> <ol style="list-style-type: none"> <li>Information and support on taking responsibility for their own care.</li> <li>The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services</li> <li>A named coordinator for the transfer of care</li> <li>A preparation period prior to transfer</li> <li>Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards</li> <li>Advice for young people leaving home or studying away from home including: <ol style="list-style-type: none"> <li>registering with a GP</li> <li>how to access emergency and routine care</li> <li>how to access support from their specialist service</li> <li>communication with their new GP</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>This QS is normally applicable only to SHTs. If networks agree to transition directly to LHTs then this QS is applicable also to these teams. This QS applies to both adult and paediatric services as both need to be involved in the transfer of care.</li> <li>Additional information on transition to adult services and preparation for adult life is available from 'Ready Steady Go' and other similar transition programmes.</li> <li>Arrangements should comply with national guidance for Looked After Children - Preparing for Independence  <a href="https://www.nice.org.uk/guidance/ph28">https://www.nice.org.uk/guidance/ph28</a></li> <li>Transition should cover all aspects of a young person's needs, including their psychosocial and emotional needs. Specialist services should be involved in transition planning for young people with more complex needs (eg. disability, mental health or chronic pain) to ensure that all aspects of their needs are taken in account.</li> </ol>
<p>HC-197</p>	<p><b>Gathering Views of Children, Young People and their Families</b>  The service should gather the views of children, young people and their families at least every three years using:</p> <ol style="list-style-type: none"> <li>'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder'</li> <li>UKTS Survey for Parents of Children with Thalassaemia</li> </ol>	<ol style="list-style-type: none"> <li>Survey questionnaires for use in this QS can be accessed on: <a href="https://www.picker.org/tools-resources/toolkits/">https://www.picker.org/tools-resources/toolkits/</a></li> <li>A 10% response rate for patient surveys is the minimum expected for compliance with this QS.</li> <li>Discussion of responses and actions required is covered by QS HC-797.</li> </ol>

<p>HC-198</p>	<p><b>Network-wide Involvement of Children, Young People and Families</b>                  The HCC should have mechanisms for involving children, young people and their families, including representation at HCC Business Meetings (QS HC-702).</p>	
<p>HC-199</p>	<p><b>Involving Children, Young People and Families</b>                  The service’s involvement of children, young people and their families should include:                  a. Mechanisms for receiving feedback                  b. Mechanisms for involving patients and their carers in: i. decisions about the organisation of the service ii. discussion of patient experience and clinical outcomes (QS HC-797)                  c. Examples of changes made as a result of feedback and involvement</p>	<p>1. The arrangements may be part of Trust-wide mechanisms so long as issues relating to haemoglobin disorder services can be identified. 2. It is desirable that paediatric and adult services collaborate on involving young people and obtaining feedback on transition arrangements.</p>

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