

Quality Standards

Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders

Version 1

July 2018

These Quality Standards may be reproduced and used by NHS and social care organisations in the UK for the purpose of improving health services for people with inherited and acquired haemophilia and other bleeding disorders. No part of the Quality Standards may be reproduced by other organisations or individuals or for other purposes without the permission of the West Midlands Quality Review Service and the UK Haemophilia Centre Doctors' Organisation. Organisations and individuals wishing to reproduce any part of the Quality Standards should email the West Midlands Quality Review Service on: swb-tr.SWBH-GM-WMQRS@nhs.net.

Whilst the West Midlands Quality Review Service and the UK Haemophilia Centre Doctors' Organisation have 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 West Midlands Quality Review Service and the UK Haemophilia Centre Doctors' Organisation 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: July 2021 at the latest

Version No	Date	Change from previous version
V1	04.07.18	

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INTRODUCTION

These Quality Standards were developed by a Working Party of the UK Haemophilia Doctors' Organisation (UKHCDO) working with the West Midlands Quality Review Service (WMQRS). Membership of the Working Party is shown in Appendix 1. The Standards build on the proforma used by the UKHCDO for its previous audit programme and are consistent with the NHS England Service Specification B05/S/a for Haemophilia (All ages) which also includes a full list of conditions and their ICD 10 codes. The Standards will be used for peer review of services for people with inherited and acquired bleeding disorders. Services can also use them for showing compliance with the Service Specification and with the Care Quality Commission Key Lines of Enquiry.

AIMS OF THE QUALITY STANDARDS

The Quality Standards aim to improve the quality of care of people with inherited and acquired haemophilia and other bleeding disorders 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. Providers and commissioners should be moving towards meeting all applicable Quality Standards within the next two to five years. APPENDIX 2 lists the references sources on which the Quality Standards are based.

Through use of the Quality Standards it is hoped that:

1. The local community, service users and carers will know more about the services they can expect.
2. 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.
3. Service providers and commissioners will work together to improve service quality.
4. Service providers and commissioners will have external assurance of the quality of local services.
5. Reviewers will learn from taking part in review visits.
6. Good practice will be shared.
7. Service providers and commissioners will have better information to give to the Care Quality Commission.

SCOPE OF THE QUALITY STANDARDS

These Quality Standards relate to the care of people with inherited and acquired haemophilia and other bleeding disorders (IABD) which include:

1. Haemophilia A
2. Haemophilia B
3. Von Willebrand Disease
4. Acquired haemophilia
5. Inherited platelet disorders
6. Other less common and rare inherited bleeding disorders

The following are not covered by the Quality Standards:

1. The care of patients with other acquired coagulation disorders in any clinical setting (for example, trauma, critical care, surgery, liver disease or obstetrics).
2. General haemostasis services including anticoagulation treatment or the reversal of anticoagulation treatment.

Care for people with inherited and acquired bleeding disorders is provided by Haemophilia Comprehensive Care Centres (HCCCs) which have been defined in the NHS England Service Specification as providing comprehensive care for at least 40 severely affected patients. Comprehensive Care Centres provide 24 hour specialist treatment, including 24 hour advice and support to Haemophilia Centres (HC) with which they are linked. HCCCs and HCs are expected to work together in a managed clinical network which should include at least one HCCC. Networks are expected to agree clear pathways which ensure all patients have access to comprehensive care 24 hours a day, seven days a week, including protocols for out-of-hours care, emergency management and treatment of inhibitors.

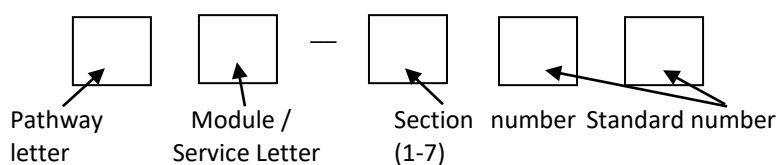
The Quality Standards for the Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders are appropriate for use by all HCCCs. Many of the standards are also applicable to larger HCs. The Standards also include links between these services and smaller units. Haemophilia Centres with a very small number of patients may wish to use the Standards as the principles of care are applicable but some discretion may be needed in their interpretation.

The Quality Standards for the Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders should sit within organisations' overall clinical governance arrangements. The WMQRS Clinical Governance Quality Standards describe the clinical governance arrangements which should be in place. Compliance in NHS provider organisations will usually be assured through other regulatory bodies. Latest versions of these and other WMQRS Quality Standards are available on the WMQRS website www.wmQRS.nhs.uk.

STRUCTURE OF THE QUALITY STANDARDS

WMQRS QUALITY STANDARDS REFERENCE STRUCTURE

WMQRS Quality Standard reference numbers have the following structure:



Each Standard is structured as follows:

Reference Number (Ref)	<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"> <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										
Quality Standard (QS)	This describes the quality that services are expected to provide.										
Notes	<i>The notes give more detail about either the interpretation or the applicability of the Standard.</i>										

Pathway and Service Letters:

The Quality Standards for the Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders use the pathway letter 'H'. The Standards are in the following sections:

HP**	Specialist Service	These Standards are applicable to services whose prime function is the care of people with inherited and acquired haemophilia and other bleeding disorders.
HX**	Network	These Standards are applicable to the managed clinical network of at least one Comprehensive Care Centre and linked Haemophilia Centres and are the responsibility of Comprehensive Care Centres.
HZ**	Commissioning	These QS are applicable to NHS England commissioners of services for people with inherited and acquired haemophilia and other bleeding disorders.

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; this is so 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 3 . A Glossary of Terms and Abbreviations is given in Appendix 4.

EXCEL AND PDF VERSIONS

The full text of the Quality Standards and all Appendices are available on the WMQRS website www.wmqrs.nhs.uk in a PDF version. A self-assessment form is available in Excel and it is recommended that this is used by services when considering their compliance with the Standards. The Excel version has the following advantages:

- The spreadsheet includes a 'CQC' tab. This updates automatically when a self-assessment is completed and allows services to see, and demonstrate, the extent to which they are achieving the CQC Key Lines of Enquiry.

When using the Excel spread-sheet 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.

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 considered when the Standards are updated. Comments should be sent to swb-tr.SWBH-GM-WMQRS@nhs.net

More information about WMQRS and its Quality Standards and reviews is available at www.wmqrs.nhs.uk or 0121 612 2146.

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QUALITY STANDARDS

HAEMOPHILIA COMPREHENSIVE CARE CENTRES AND HAEMOPHILIA CENTRES

Ref	Standard					
INFORMATION AND SUPPORT FOR PATIENTS AND CARERS						
<p>HP-101</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: #d9e1f2;">BI</td></tr> <tr><td style="background-color: #d9e1f2;">Visit</td></tr> <tr><td style="background-color: #d9e1f2;">MP&S</td></tr> <tr><td style="background-color: #d9e1f2;">CNR</td></tr> <tr><td style="background-color: #d9e1f2;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>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 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 HP-199) <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>Information should be written in clear, plain English and should be available in formats and languages appropriate to the needs of the patients, including developmentally appropriate information for young people and people with learning disabilities. Information for young people should meet the 'Quality Criteria for Young People Friendly Health Services' (DH, 2011).</i> 2. <i>Information may be in paper or electronic/e-learning formats or in the form of a website or other social media. Guidance on how to access information is sufficient for compliance so long as this points to easily available information of appropriate quality. If the information is provided only in individual patient letters then examples will need to be seen by reviewers.</i> 3. <i>This QS is about signposting to relevant services. The actual services available may be different in different areas.</i>
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<p>HP-102</p> <table border="1" data-bbox="204 280 290 459"> <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>Condition-Specific 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. A description of their condition and how it might affect them b. How their condition is diagnosed c. Genetics of inherited bleeding disorders d. Testing for carrier status and the implications of being a carrier e. Problems, symptoms and signs for which emergency advice should be sought f. Out of hours services g. 'On demand' clotting factor treatment h. Prophylaxis i. Self infusion (or infusion by parent or carer) j. Home therapy and use of Haemtrack k. How to manage bleeding at home l. Ports, fistulae and in-dwelling access devices (if applicable) m. Possible complications, including inhibitors and long term joint damage n. Approach to elective and emergency surgery o. Women's health issues p. Health promotion, including smoking cessation, health eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being q. Dental care r. Travel advice s. Vaccination advice t. National Haemophilia Database, its purpose and benefits u. Sources of further advice and information <p>Information should be available covering:</p> <ol style="list-style-type: none"> 1. Haemophilia A 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Other less common and rare bleeding disorders <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>As QS HP-101</i> 2. <i>Information may be given at different stages of the patient pathway.</i> 3. <i>Information on women's health issues should cover, at least, contraception, pregnancy, childbirth and breast-feeding.</i> 4. <i>Travel advice information should cover the EUHANET locator of haemophilia services www.euhanet.org/centrelocator/</i> 5. <i>Information on testing for carrier status and the implications of being a carrier should include arrangements for specialist referral.</i> 6. <i>Sources of further information should cover, at least, the Haemophilia Society, World Federation of Haemophilia, UK Haemophilia Centre Doctors' Organisation.</i>
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<p>HP-103</p> <table border="1" data-bbox="204 280 290 452"> <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>Plan of Care</p> <p>Each patient and, where appropriate, their carer should discuss and agree their Plan of Care, and should be offered a written record covering at least:</p> <ol style="list-style-type: none"> Agreed goals, including life-style goals Self-management Planned assessments, therapeutic and/or rehabilitation interventions Early warning signs of problems, including acute exacerbations, and what to do if these occur Agreed arrangements with school or other education provider and preparation for adult life (children and young people only) Planned review date and how to access a review more quickly, if necessary Who to contact with queries or for advice <p>The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>This QS is about a holistic view of the patient's needs and how they will be met. Plans of care may be in the form of clinic letters or patient-held records so long as all aspects of the QS are covered.</i> <i>Some patients may need additional detail in their Plan of Care, for example, people with learning disabilities or those who are resident in a care home.</i> <i>Planned therapeutic interventions include planned surgery as well as pharmacological and non-pharmacological therapies</i> <i>Data collection for the number of patients receiving home treatment is covered in HP-701</i>
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<p>HP-104</p> <table border="1" data-bbox="204 1137 290 1310"> <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 of Plan of Care</p> <p>A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>As QS HP-103 note 1.</i> <i>A longer review duration may be appropriate in some conditions where there are specific clinical indications for specialist review at these times.</i>
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<p>HP-105</p> <table border="1" data-bbox="204 1552 290 1724"> <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>Contact for Queries and Advice</p> <p>Each patient and, where appropriate, their carer should have a contact point within the service for queries and advice. A clear system for triage of urgent clinical problems should be in place. If advice and support is not immediately available for non-urgent enquiries, then the timescales for a response should be clear. Response times should be no longer than the end of the next working day. All contacts for advice and a sample of actual response time should be documented.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>The response by the end of the next working day means a response by, or following discussion with, a health or social care professional. It does not mean that a particular health or social care professional involved in the individual's care will respond by the end of the next working day.</i> <i>This 'advice line' may also provide an advisory service for general practitioners, dental practitioners and staff working in other health and social services.</i>
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HP-106 <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	Haemtrack (Patients on Home Therapy) All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack.
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HP-194 <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	Environment The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of patients with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. 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. <i>Notes:</i> 1. <i>Required facilities and equipment are not strictly defined but should be appropriate for the usual number and case mix of patients cared for by the service.</i> 2. <i>Evidence of admissions of patients to other clinical areas may be used in determining compliance with this QS.</i>
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HP-195 <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	Transition to Adult Services and Preparation for Adult Life Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards f. Advice for young people going away from home to study, including: i. registering with a GP ii. how to access emergency and routine care iii. how to access support from their Comprehensive Care Centre iv. communication with their new GP <i>Notes:</i> 1. <i>The 'Ready Steady Go' transition programme provides additional information on transition to adult services and preparation for adult life.</i> 2. <i>Arrangements should comply with national guidance for Looked After Children - Preparing for independence https://www.nice.org.uk/guidance/ph28</i>
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HP-198 <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	Carers' Needs Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support <i>Notes:</i> 1. <i>Support for carers may include carer's breaks, emergency response, support for other family members and access to practical and psychological support.</i>
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<p>HP-201</p> <table border="1" data-bbox="204 784 290 963"> <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 and Lead Nurse</p> <p>A nominated lead consultant and lead nurse should have responsibility for staffing, training, guidelines and protocols, service organisation, governance and for liaison with other services. The lead consultant and lead nurse should be registered healthcare professionals with appropriate specialist competences and should undertake regular clinical work within the service and specific time allocated for their leadership role.</p>
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<p>HP-202</p> <table border="1" data-bbox="204 1030 290 1209"> <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>Staffing Levels and Skill Mix</p> <p>Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include:</p> <ol style="list-style-type: none"> Medical staff: <ol style="list-style-type: none"> Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours On-call consultant haematologist (24/7) Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) Specialist nursing staff: <ol style="list-style-type: none"> Bleeding disorders specialist nurses (5/7) Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. Clinical specialist physiotherapist Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) Clinical or counselling specialist psychologist or appropriately trained psychotherapist Specialist senior social worker Data manager
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	<p>Notes:</p> <ol style="list-style-type: none"> 1. A clear methodology should, ideally, be used to determine appropriate staffing levels and skill mix. Staff should have time allocated for their role in the service but roles may be part-time and staff may be shared with other services. In this QS, 'specialist' means that staff have specialist expertise in the care of people with inherited and acquired bleeding disorders. Reviewers should be concerned about the availability of staff with appropriate competences rather than management arrangements. Reviewers should note the number of Programmed Activities (PA) sessions available and the number of patients for whom care is provided. 2. Medical Staff: If doctors in training are used to achieve this QS, they should have dedicated, supervised time allocated to developing their expertise in inherited and acquired bleeding disorders. This may include attending and participating in out-patient clinics, attending multi-disciplinary team meetings, time for development of laboratory skills, undertaking audits and management of in-patients with inherited and acquired bleeding disorders. 3. Nursing Staff: Any specialist nurses should have completed an appropriate post-registration (LBR) education programme, for example, the Contemporary Care Course (previously Essentials and/or Advising Haemophilia Courses). A specialist inherited and acquired bleeding disorders nurse should be able to: <ol style="list-style-type: none"> a. assess patients b. manage episodes of care and home treatment programmes, possibly including prescribing c. refer patients to other healthcare professionals as necessary d. teach patients, families and other hospital staff about inherited and acquired bleeding disorders and their treatment e. evaluate outcomes 4. Clinical specialist physiotherapist: A specialist inherited and acquired bleeding disorders physiotherapist should be able to: <ol style="list-style-type: none"> a. assess and treat patients b. teach patients, families and other hospital staff about inherited and acquired bleeding disorders and their treatment c. attend and participate in out-patient clinics, attend multi-disciplinary team meetings d. liaise with other haemophilia centres as necessary e. evaluate outcomes <p>More detail of the recommended physiotherapy staffing is given in the HCPA UK standards of care.</p> 5. Specialist psychology staff should be able to see urgent referrals within three week and non-urgent referrals within six to eight weeks. Further guidance on the contribution of psychology services to the care of people with inherited and acquired bleeding disorders is being prepared by the Haemophilia Psychology Association (HPA) and should be available in 2018. 6. Specialist social workers should be able to see urgent referrals within one week and non-urgent referrals within six to eight weeks. 7. Involvement of a senior biomedical laboratory scientist or clinical scientist in the work of the team is covered in QSs HP-303 and HP-602. 8. Competences should be appropriate to role responsibilities and include relevant training and supervision. Competences for Nurses are accessible from 'Haemnet' https://www.haemnet.com/external/homepage 9. Specialist nurses and physiotherapists should belong to the UKHCDO Haemophilia Nurses Association or Haemophilia Chartered Physiotherapist Association.

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<p>HP-203</p> <table border="1" data-bbox="204 280 290 452"> <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>Service Competences and Training Plan</p> <p>The competences expected for each role in the service should be identified. A training and development plan for achieving and maintaining competences should be in place.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>This QS is about the needs of the service and cannot be met solely by individual staff appraisals and personal development reviews (PDRs). Appraisals and PDRs are sufficient for maintenance of competence. Details of individual appraisals and PDRs are not required. Reviewers may, however, 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> 2. <i>For compliance with this QS the service should provide:</i> <ol style="list-style-type: none"> a. <i>A matrix of the roles within the service, competences expected and approach to maintaining competences</i> b. <i>A training and development plan showing how competences are being achieved and maintained.</i> 3. <i>Training may be delivered through a variety of mechanisms, including e-learning, Trust-wide training and departmental training.</i>
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<p>HP-204</p> <table border="1" data-bbox="204 952 290 1124"> <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>Competences – All Health and Social Care Professionals</p> <p>All health and social care professionals working in the service should have competences appropriate to their role in:</p> <ol style="list-style-type: none"> a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>Role-specific mandatory training may cover more than the competences included in this QS.</i>
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<p>HP-299</p> <table border="1" data-bbox="204 1366 290 1538"> <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 available.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>The amount of administrative and clerical 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.</i>
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SUPPORT SERVICES						
<p>HP-301</p> <table border="1" data-bbox="204 369 290 548"> <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>Support Services</p> <p>Timely access to the following support services should be available:</p> <ol style="list-style-type: none"> a. Play support (children's services only) including: <ol style="list-style-type: none"> i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>Timely is not strictly defined but should ensure that patient pathways and the service's timescales for assessments and therapeutic and/or rehabilitation interventions are not unreasonably delayed. Specific indications for referral to, and timescales for response by, support services may be agreed.</i> 2. <i>These services may be hospital or community-based so long as patients have access to services when at home and when admitted to hospital.</i>
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<p>HP-302</p> <table border="1" data-bbox="204 974 290 1153"> <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 should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of:</p> <ol style="list-style-type: none"> a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>This QS applies to Emergency Departments normally attended by people with inherited and acquired bleeding disorders.</i>
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<p>HP-303</p> <table border="1" data-bbox="204 1355 290 1534"> <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 Service</p> <ol style="list-style-type: none"> a. A UKAS / CPA accredited laboratory service with satisfactory External Quality Assurance performance should be available 24/7 b. A laboratory representative (senior biomedical scientist or clinical scientist) should attend inherited and acquired bleeding disorder service multi-disciplinary team meetings (QS HP-602) regularly c. The following tests should be available: <ol style="list-style-type: none"> i. All coagulation factor assays (24/7) ii. Inhibitor screening iii. FVIII inhibitor quantification iv. VWF antigen v. VWF activity vi. Platelet function testing d. Molecular Genetic Laboratory service for: <ol style="list-style-type: none"> i. detection of causative mutations in patients with inherited bleeding disorders ii. carrier detection
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<p>HP-304</p> <table border="1" data-bbox="204 280 290 452"> <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</p> <p>Timely access to the following specialist staff and services should be available as part of a HCCC service. HCs should be able to access these services through network arrangements:</p> <ol style="list-style-type: none"> Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis Foetal medicine Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) Orthopaedic surgery Care of older people services Dental services HIV services Hepatology Medical genetics (Genetic Counselling Services) Pain management services Rheumatology <p>Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> As QS HP-301 note 1. Some of the above may not be applicable to children's IABD services.
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<p>FACILITIES AND EQUIPMENT</p>						
<p>HP-402</p> <table border="1" data-bbox="204 1227 290 1400"> <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>Facilities and Equipment</p> <p>Facilities and equipment appropriate for the service provided should be available including:</p> <ol style="list-style-type: none"> Fridges Storage Clinical rooms for staff of all disciplines to see patients and carers Room for multi-disciplinary discussion Room for educational work with patients and carers Office space for staff Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas <p>All equipment should be appropriately checked and maintained.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> As QS HP-194. Timely availability of equipment is not strictly defined but availability of equipment, including consumables, should not unreasonably delay patient pathways or adversely affect patient outcomes and experience. Rooms may be used for more than one purpose.
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<p>HP-499</p> <table border="1" data-bbox="204 280 290 452"> <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>IT System</p> <p>IT systems should be in use for:</p> <ol style="list-style-type: none"> Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree Patient administration, clinical records and outcome information Data to support service improvement, audit and revalidation Alerting the specialist team when patients attend the Emergency Department <p><i>Notes:</i></p> <ol style="list-style-type: none"> IT and records systems should be integrated to avoid duplicate entry of patient data. The ability to transmit data to the National Haemophilia Database without re-entry of data is therefore a requirement for this QS. This QS may be achieved through use of the Haemophilia Centre Information System (HCIS) or equivalent.
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<p>GUIDELINES AND PROTOCOLS</p>						
<p>HP-501</p> <table border="1" data-bbox="204 918 290 1090"> <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>Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders</p> <p>Guidelines on diagnosis should be in use covering at least</p> <ol style="list-style-type: none"> Haemophilia A Haemophilia B Von Willebrand Disease Acquired haemophilia Inherited platelet disorders Other less common and rare bleeding disorders <p><i>Notes:</i></p> <ol style="list-style-type: none"> Guidelines should be based on national guidance, including NICE and UKHCDO guidance and the commissioned local pathway. Guidelines should be localised to show how national guidance will be implemented in the local situation. Use of national guidance without consideration of local implementation is not sufficient for compliance with this QS. Guidelines should include: <ol style="list-style-type: none"> Genetic testing and genetic counselling Identification of potential carriers and offering genetic counselling and testing
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<p>HP-502</p> <table border="1" data-bbox="204 280 290 459"> <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>Guidelines: Concentrate Use and Monitoring</p> <p>Guidelines should be in use covering:</p> <ol style="list-style-type: none"> a. Concentrate therapy: <ol style="list-style-type: none"> i. Initiation and monitoring of prophylaxis ii. Home therapy b. Use of extended half life products, including inhibitor testing and PK assessment c. Management of concentrate supplies including: <ol style="list-style-type: none"> i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised iv. Prescription and delivery for patients on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to patients vii. Recording use by patients, including on Haemtrack viii. Submission of data via NHD for national tenders coordinated by CMU <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. Arrangements for management of factor concentrates may be network-wide or may be locally agreed.
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<p>HP-503</p> <table border="1" data-bbox="204 996 290 1176"> <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</p> <p>The following clinical guidelines should be in use:</p> <ol style="list-style-type: none"> a. Management of acute bleeding episodes, including patients with inhibitors b. Inhibitor screening c. Immune tolerance therapy d. Dental care e. Care of patients with hepatitis C f. Care of patients with HIV g. Antenatal care, delivery and care of the neonate h. Management of synovitis and target joints i. Long term surveillance of musculoskeletal health j. "For public health purposes": care of patients at risk of vCJD who are undergoing surgery <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. As QS HP-501. 2. HC guidelines should include indications for escalation to the HCCC and should be consistent with those in use in their linked HCCC. 3. Some of the above may not be applicable to children's IABD services.
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<p>HP-504</p> <table border="1" data-bbox="204 1657 290 1836"> <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 Guidelines</p> <p>Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.</p>
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<p>HP-505</p> <table border="1" data-bbox="204 280 290 452"> <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>Guidelines on Care of Patients requiring Surgery</p> <p>Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least:</p> <ol style="list-style-type: none"> Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery Communication of the agreed plan of care to all staff involved in the patient's care prior to, during and post-surgery Documentation of care provided Arrangements for escalation in the event of unexpected problems
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<p>HP-595</p> <table border="1" data-bbox="204 638 290 810"> <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>Guidelines on Transition and Preparing for Adult Life</p> <p>Guidelines on transition of young people from paediatric to adult services should be in use covering at least:</p> <ol style="list-style-type: none"> Taking responsibility for their own care Involvement of the young person and, where appropriate, their carer in planning the transfer of care Joint meeting between paediatric and adult services in order to plan the transfer Allocation of a named coordinator for the transfer of care A preparation period prior to transfer Arrangements for monitoring during the time immediately after transfer Advice for young people going away from home to study, including: <ol style="list-style-type: none"> registering with a GP how to access emergency and routine care how to access support from their Comprehensive Care Centre communication with the young person's new GP <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>This QS applies only to services where significant numbers of young people transfer from paediatric services. The QS applies to both paediatric and adult service and transition guidelines should be agreed between relevant paediatric and adult services.</i> <i>The 'Ready Steady Go' transition programme provides additional information on transition to adult services and preparation for adult life</i> <i>The General Practitioner should be informed / given the opportunity to be involved in the transition of young people from paediatric to adult services.</i> <i>Guidelines should be clear about responsibility and arrangements for sharing of information between paediatric and adult services and between the HCCC and services located where a young person is studying.</i>
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HP-599 <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: #0056b3; color: white;"><td style="text-align: center;">MP&S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #0056b3; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Care of Vulnerable People</p> <p>Guidelines for the care of vulnerable children, young people and adults should be in use including:</p> <ol style="list-style-type: none"> a. Restraint and sedation b. Missing patients c. Mental Capacity Act and the Deprivation of Liberty Safeguards d. Safeguarding e. Information sharing f. Palliative care g. End of life care <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>This is a linking QS and will not be reviewed in detail. Any lack of compliance seen during review visits will, however, be noted.</i>
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<p>SERVICE ORGANISATION AND LIAISON WITH OTHER SERVICES</p>						
HP-601 <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: #0056b3; color: white;"><td style="text-align: center;">MP&S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #0056b3; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Service Organisation</p> <p>The service should have an operational procedure covering at least:</p> <ol style="list-style-type: none"> a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for patients with inherited and acquired bleeding disorders responsible for their care b. Ensuring all adults are under the care of a consultant haematologist with an interest in inherited and acquired bleeding disorders, either directly or through a shared care arrangement with a general haematologist c. Responsibility for giving information and education at each stage of the patient journey d. Arrangements for involving Haemophilia Centre staff in multi-disciplinary discussions relating to their patients (QS HP-602) e. Arrangements for follow up of patients who 'do not attend' f. Arrangements for transfer of patient information when patients move areas temporarily or permanently g. Ensuring patients' plans of care are reviewed at least six monthly for patients with severe haemophilia and at least annually for other patients (QS HP-104) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring patients are visited at home at least annually if they are unable to attend clinics, including those in nursing homes j. Lone working <p><i>Notes:</i></p> <ol style="list-style-type: none"> 1. <i>If a named paediatric haematologist with an interest in inherited and acquired bleeding disorders is responsible for a child's care then only one responsible consultant is required.</i>
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HP-602 <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: #0056b3; color: white;"><td style="text-align: center;">MP&S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #0056b3; color: white;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p>Multi-Disciplinary Team Meetings</p> <p>Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving:</p> <ol style="list-style-type: none"> a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the patient's care as part of network arrangements
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<p>HP-603</p> <table border="1" data-bbox="204 280 290 459"> <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 Clinics</p> <p>The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place:</p> <ol style="list-style-type: none"> Involvement of medical, specialist nursing and physiotherapy staff in clinics Availability of social work and psychology staff in clinics Combined clinics or other arrangements for multi-disciplinary discussion with: <ol style="list-style-type: none"> orthopaedics rheumatology obstetrics and gynaecology paediatrics dental HIV / hepatology <p><i>Notes:</i></p> <ol style="list-style-type: none"> 'a'. This QS expects that in HCCCs these staff will be present together with the patient and their carers at the same time in order that a holistic approach to care can be discussed and agreed. 'b' Other arrangements, such as video-links, may be appropriate so long as the aim of a patient-centred, holistic discussion is achieved. 'c': HCCCs will normally have sufficient patients to hold combined clinics as described. This QS is not specific about the frequency of clinics which will depend on the size of the service. Frequency should be sufficient to ensure decisions on patient care are not unreasonably delayed. Other arrangements, such as video-links, may be appropriate so long as the aim of a patient-centre, holistic discussion is achieved. Multi-disciplinary arrangements for discussion with some services may not be applicable to children's IABD services.
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<p>HP-604</p> <table border="1" data-bbox="204 1220 290 1400"> <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>Liaison with Other Services</p> <p>Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> This QS relates to those services with which liaison is particularly important to ensure an efficient, high quality patient journey. These services should be listed in QS HP-304 but annual review meetings with all services required in QS HP-304 may not be necessary. Meetings may be part of a Trust-wide meeting so long as operational issues specific to the service are discussed. This QS is in addition to day to day liaison arrangements and should involve staff with management responsibility for the service.
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<p>GOVERNANCE</p>						
<p>HP-701</p> <table border="1" data-bbox="204 1742 290 1921"> <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>Data Collection</p> <p>The following data should be collected:</p> <ol style="list-style-type: none"> UK National Haemophilia Database data on all patients Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms <p><i>Notes:</i></p> <ol style="list-style-type: none"> Some areas are not required to submit to the UKHCDO National Haemophilia Database in which case other arrangements should be in place for the collection, submission and review of data.
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HP-706 <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	Research <p>The service should actively participate in research relating to the care of patients with bleeding disorders.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>A list of research participated in in the last three years and the number of patients recruited into research studies is appropriate documentary evidence of compliance with this QS.</i>
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HP-798 <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	Multi-disciplinary Review and Learning <p>The service should have multi-disciplinary arrangements for review of and implementing learning from:</p> <ol style="list-style-type: none"> Positive feedback, complaints, outcomes, incidents and 'near misses' Morbidity and mortality Haemophilia Dashboard Review of UKHCDO Annual Report benchmarking information on concentrate use Ongoing reviews of service quality, safety and efficiency Published scientific research and guidance
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HP-799 <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	Document Control <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>Specific documentary evidence of compliance is not required. This QS will be determined from the other documentary information provided.</i> <i>Copies of the organisations document control policies are also required for compliance with this QS</i>
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NETWORK

These Standards are applicable to the managed clinical network of at least one Comprehensive Care Centre and linked Haemophilia Centres and are the responsibility of Comprehensive Care Centres.

Ref	Standard					
INFORMATION AND SUPPORT FOR PATIENTS AND 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>
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STAFFING						
HY-203 <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	Inherited and Acquired Bleeding Disorders Network Leads <p>The network should have a nominated:</p> <ol style="list-style-type: none"> Lead consultant and deputy Lead specialist nurse Lead physiotherapist Lead clinical or counselling psychologist Lead manager <p><i>Notes:</i></p> <ol style="list-style-type: none"> <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>
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Ref	Standard					
GUIDELINES AND PROTOCOLS						
HY-503 <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	Guidelines <p>Network guidelines should have been agreed covering:</p> <ol style="list-style-type: none"> Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) Concentrate use and monitoring (QS HP-502) Clinical guidelines (QS HP-503) Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) Care of patients requiring surgery (QS HP-505) Transition and preparing for adult life (QS HP-595) <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>Guidelines should be based on national guidance, including NICE and UKHCDO guidance and the commissioned local pathway. Implementation of these guidelines is covered in QS HP-501 to HP-595.</i>
BI						
Visit						
MP&S						
CNR						
Doc						
GOVERNANCE						
HY-701 <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	Ongoing Monitoring <p>The network should monitor on a regular basis:</p> <ol style="list-style-type: none"> Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) Network-wide data on concentrate use and bleeds
BI						
Visit						
MP&S						
CNR						
Doc						
HY-702 <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	Audit <p>The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>These topics should be covered by the overall audit programme. An annual network audit is not expected.</i>
BI						
Visit						
MP&S						
CNR						
Doc						
HY-703 <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	Research <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 inherited and acquired bleeding disorders A list of research trials available to all patients within the network.
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
<p>HY-798</p> <table border="1" data-bbox="204 277 288 454"> <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>Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year 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 positive feedback, complaints, critical incidents and ‘near misses’, including those involving liaison between teams Share good practice and potential service improvements <p><i>Notes:</i></p> <ol style="list-style-type: none"> <i>Comprehensive Care Centres are responsible for ensuring Network Review and Learning meetings take place with appropriate content and that linked Haemophilia Centres are invited to attend. Haemophilia Centres are responsible for sending appropriate representatives. In some areas, Network Review and Learning Meetings will involve more than one Comprehensive Care Centre who will collaborate on arranging the meetings.</i> <i>Network review and learning meetings should address areas where collaboration between services is either necessary or desirable.</i>
BI						
Visit						
MP&S						
CNR						
Doc						

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COMMISSIONING

Ref	Standard
HZ-601 BI Visit MP&S CNR Doc	Commissioning of Services Commissioners should have agreed the configuration of clinical networks including: <ol style="list-style-type: none"> Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them Whether the service cares for children, adults or both Referral pattern to each service, taking into account the type of patients who will be treated by each team
HZ-701 BI Visit MP&S CNR Doc	Clinical Quality Review Meetings Commissioners should regularly review the quality of care provided by: <ol style="list-style-type: none"> Each service, including achievement of QS HP-701 Each network, including achievement of QS HY-701 and QS HY-798 Service and network achievement of relevant Qs
HZ-798 BI Visit MP&S CNR Doc	Network Review and Learning Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.

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APPENDIX 1 WORKING PARTY MEMBERSHIP

Name	Position	Organisation
Dr Helen Aiston	Highly Specialist Clinical Psychologist	Hampshire Hospitals NHS Foundation Trust
Dr Julia Anderson	Consultant Haematologist	Edinburgh Haemophilia Care Centre NHS Lothian
Sarah Bowman	Haemophilia Social Worker	Sheffield Teaching Hospitals NHS Foundation Trust
Sarah Broomhead	Assistant Director	WMQRS
Liz Carroll	Chief Executive	The Haemophilia Society
Dr Elizabeth Chalmers	Consultant Paediatric Haematologist	NHS Greater Glasgow and Clyde
Jane Eminson	Director	WMQRS
Dr Gillian Evans	Consultant Haematologist Director of Kent Haemophilia and Thrombosis Centre	East Kent Hospitals University Foundation Trust
Dr John Hanley	Consultant Haematologist UKHCDO Peer Review Group Chair	The Newcastle upon Tyne Hospitals NHS Foundation Trust
Cathy Harrison	Haemophilia & Thrombosis CNS/ANP	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Lishel Horn	Consultant Haematologist Director of Leeds Haemophilia Centre (adults)	The Leeds Teaching Hospitals NHS Trust
Dr Kate Khair	Haemophilia Nurse Consultant	Great Ormond Street Hospital for Children NHS Foundation Trust
Graham Knight	Patient Representative	
Dr Ri Liesner	UKHCDO Chair, Consultant in Paediatric Haemostasis and Thrombosis	Great Ormond Street NHS Foundation Trust
Dr Rhona MacLean	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Tim Nokes	Consultant Haematologist	Plymouth Hospitals NHS Trust
Anna Wells	Clinical Specialist Physiotherapist Chair Haemophilia Chartered Physiotherapists Association (HCPA)	Hampshire Hospitals NHS Foundation Trust
Lianne Willey	Patient Representative	
Dr Anne Yardumian	Consultant Haematologist	North Middlesex University Hospital NHS Trust

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APPENDIX 2 REFERENCE SOURCES

Year	Publisher	Title	Number
2017	Care Quality Commission	Key lines of enquiry	1
2017	NHSE	Next steps on the five year forward view	2
2017	Haemophilia (2017) 1-10	Guideline for the management of acute joint bleeds and chronic synovitis in haemophilia	3
2017	UKHCDO	UKHCDO protocol for first line immune tolerance induction for children with severe haemophilia A: a protocol by the UKHCDO inhibitor and paediatric working parties	4
2017	Haemophilia Chartered Physiotherapists Association (HCPA)	Service Provision of Physiotherapy for Adults with Haemophilia & other Inherited Bleeding Disorders	5
2017	Haemophilia Chartered Physiotherapists Association (HCPA)	Service Provision of Physiotherapy for Children with Haemophilia & other Inherited Bleeding Disorders	6
2017	Haemophilia Society	Understanding Haemophilia	7
2016	Haemophilia (2016) 22, 487-498	The use of enhanced half-life coagulation factor concentrates in routine clinical practice: guidance from UKHCDO	8
2015	Haemophilia Society	Understanding von Willebrand disease	9
2015	UKHCDO	Guideline on clinical genetic services for haemophilia	10
2015	UKHCDO	Protocol for first line immune tolerance induction for children with severe haemophilia A	11
2015	Think Local Act Personal (TLAP)	An online tool for commissioners, planners, clinicians and practitioners involved in designing and delivering personalised care and support planning for people with a variety of health and social care needs	12
2015	NHS IQ	Seven-day service	13
2014	Haemophilia Volume 19, issue 3 pages e191 to e192, May 2013	Guideline for the diagnosis and management of the rare coagulation disorders	14
2014	Br J Haematology 10.1111/bjh.13064	The diagnosis and management of von Willebrand disease: a UKHCDO guideline approved by the British Committee for standards in haematology with inherited coagulation	15
2013	Haemophilia volume 19, Issue 3 pages	Update to UKHCDO guidance on	16

	e191-e192, May 2013	vaccination against Hepatitis A and B viruses in patients with inherited coagulation factor deficiencies and von Willebrand disease.	
2013	British Dental Journal 215:497-504, 2013	Guidance on dental management of patients with haemophilia and congenital bleeding disorders	17
2013	Br J Haematology 160:153-170, 2013	Diagnosis and treatment of factor VIII and IX inhibitors in congenital haemophilia (4 th Edition)	18
2013	Br J Haematology 162:758-773, 2013	Diagnosis and management of acquired coagulation inhibitors: a guideline from UKHCDO	19
2012	HQIP	Template for clinical audit	20
2012	Royal College of Physicians	Clinical documentation and generic record standards (CDGRS) Project: phase 2	21
2012	NICE	Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services NICE CG 138	22
2013	HSCIC	Standards for the clinical structure and content of patient records	23
2013	NHSE	Putting patients first: The NHS Business plan	24
2013	Robert Francis QC	Report of the Mid Staffordshire NHSFT public enquiry	25
2011	Br J Haematology 154:208-215	Guideline on the management of haemophilia in the foetus and neonate	26
2010	CMGS Website	Practice guidelines for the molecular diagnosis of haemophilia A	27
2010	CMGS Website	Practice guidelines for the molecular diagnosis of haemophilia B	28
2010	Br J Haematology 149, 498-507	UKHCDO guideline approved by the British committee for standards in haematology: guideline for the use of prophylactic factor VIII concentrate in children and adults with severe haemophilia A	29
2010	NICE	Looked After Children - Preparing for independence	40
2009	UKHCDO Website	Emergency and out of hours care for patients with bleeding disorders – standards of care for assessment and treatment	30
2009	Department of Health and Department for children, schools and families	Health lives, brighter futures – the strategy for children’s and young peoples health	31

2008	Haemophilia 14, 1099-1111	The molecular analysis of von Willebrand disease: a guideline from the UKHCDO haemophilia genetics laboratory network	32
2008	Medical Conditions at school	Medical conditions at school policy resource pack. http://medicalconditionsatschool.org.uk	33
2008	Haemophilia 14, 671-684	Guideline on the selection and use of therapeutic products to treat haemophilia and other hereditary bleeding disorders. A UKHCDO guideline approved by the British committee for standards in haematology	34
2006	Haemophilia 12, 301-336	The obstetric and gynaecological management of women with inherited bleeding disorders review with guidelines produced by a taskforce of UKHCDO	35
2006	Br J Haematol 135, 603-633	A review of inherited platelet disorders with guidelines for their management on behalf of the UKHCDO	36
2006	The Haemophilia Alliance	National service specification for haemophilia and other inherited bleeding disorders	37
2005	Haemophilia 11, 145-163	A framework for genetic service provision for haemophilia and other inherited bleeding disorders	38
2004	Department of Health	Every Child Matters: Change for children	39

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

QS reference	Guidance documents	QS reference	Guidance documents	QS reference	Guidance documents
HP-101	1	HP-303	1	HP-706	1
HP-102	1, 7, 9, 22	HP-304	1	HP-798	1
HP-103	1, 21, 22, 23, 31	HP-402	1	HP-799	1
HP-104	1	HP-499	1, 21, 23	HY-199	1
HP-105	1, 7, 9	HP-501	1, 3, 15, 26, 27, 28, 29	HY-203	1
HP-106	1, 33	HP-502	1, 8, 26, 27, 28, 29, 34	HY-204	1
HP-194	1	HP-503	1, 3, 4, 10, 11, 14, 16, 17, 18, 19, 26, 27, 28, 29, 32, 34, 35, 36	HY-503	1, 10, 11, 14, 16, 17, 18, 19, 26, 27, 28, 29, 34, 35, 36
HP-195	1, 39, 40	HP-504	1, 30	HY-701	1

HP-198	1, 21, 23	HP-505	1, 26, 27, 28, 29	HY-702	1
HP-199	1	HP-595	1, 21, 23, 31, 39	HY-703	1
HP-201	1, 25	HP-599	1	HY-798	1
HP-202	1, 25	HP-601	1, 21, 23, 37, 38	HZ-601	1, 12, 13, 37, 38
HP-203	1, 21,23, 25	HP-602	1, 21, 23	HZ-701	1, 20
HP-204	1, 25	HP-603	1	HZ-798	1
HP-299	1	HP-604	1		
HP-301	1, 5, 6	HP-701	1, 20		
HP-302	1	HP-702	1, 20		

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APPENDIX 3 CROSS-REFERENCES TO BRITISH STANDARDS INSTITUTION PAS16:16 AND CARE QUALITY COMMISSION KEY LINES OF ENQUIRY

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

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

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

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

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

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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
HP-504	6, 8, 9		X					X				X	X	X	X												
HP-505	6, 8, 9		X					X				X	X	X	X												
HP-595	6, 8, 9		X					X				X	X	X	X												
HP-599	6, 8, 9	X	X					X		X		X	X	X	X	X	X										
HP-601	6, 7, 8, 9, 10, 11, 12	X	X	X		X	X			X			X	X		X	X	X					X	X	X	X	X
HP-602	3., 4, 7, 8, 11				X	X	X	X	X										X			X	X	X	X	X	X
HP-603	3., 4, 7, 8, 11				X	X	X	X	X										X			X	X	X	X	X	X
HP-604	4, 6			X								X						X									
HP-701	3., 4, 7, 8, 11					X	X	X	X		X							X			X		X	X	X	X	X
HP-702	3., 4, 7, 8, 11					X	X	X	X									X					X	X	X	X	X
HP-706	6, 11								X																		X
HP-798	3., 4, 7, 8, 11				X	X	X	X	X										X			X	X	X	X	X	X
HP-799	5			X																							
HY-199	3, 6, 7	X					X								X			X									X
HY-203	4, 10, 12		X					X		X										X	X	X		X	X		
HY-204	4, 10, 12		X					X		X											X	X		X	X		
HY-503	6, 8, 9		X					X				X	X	X	X												
HY-701	3, 4, 7, 8, 11					X	X	X	X		X							X			X		X	X	X	X	X
HY-702	3, 4, 7, 8, 11					X	X	X	X									X					X	X	X	X	X
HY-703	6, 11								X																		X
HY-798	3, 4, 7, 8, 11				X	X	X	X	X										X			X	X	X	X	X	X
HZ-601	3, 6, 7, 8, 9, 10, 11			X	X			X				X	X					X	X	X		X		X			

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
HZ-701	3, 4, 7, 8, 11					X	X	X	X		X							X			X		X	X	X	X	X	X
HZ-798	3, 4, 7, 8, 11				X	X	X	X	X									X				X	X	X	X	X	X	X

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APPENDIX 4 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's about making sure that people can make their own choices in life and have the chance to be as independent as they want to be.
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.
CQC	The Care Quality Commission is the independent regulator of health and social care in England.
DH	Department of Health.
Doc	Documentation should be available. Documentation may be in the form of a website or other social media.
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.
HCCC	Haemophilia Comprehensive Care Centre
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.
IABD	Inherited and acquired bleeding disorders
LBR	Learning beyond registration.
MP&S	Meeting patients, carers and staff.
NICE	National Institute for Health and Care Excellence.
NHSLA	NHS Litigation Authority.
NVQ	National Vocational Qualification.
PDR	Performance Development Review.
Provider	A health or social care organisation which provides services to patients.
QS	Quality Standard.
Service provider	See 'Provider'.
Service commissioner	See 'Commissioner'.
Trust	A NHS Trust, NHS Foundation Trust or other organisation with management responsibility for the service.
WMQRS	West Midlands Quality Review Service

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APPENDIX 5 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	
HP-101	Service Information		X	X		X	Patient information about the service
HP-102	Condition-Specific Information		X	X		X	Patient information about specific conditions
HP-103	Plan of Care			X	X		
HP-104	Review of Plan of Care			X	X		
HP-105	Contact for Queries and Advice		X	X			
HP-106	Haemtrack (Patients on Home Therapy)			X			
HP-194	Environment		X				
HP-195	Transition to Adult Services and Preparation for Adult Life			X	X		
HP-198	Carers' Needs			X			
HP-199	Involving Patients and Carers			X		X	Examples of changes made as a result of feedback

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	
HP-201	Lead Consultant and Lead Nurse	X					
HP-202	Staffing Levels and Skill Mix	X		X		X	Examples of staff rotas
HP-203	Service Competences and Training Plan			X		X	Competence Framework and Training Plan: <ul style="list-style-type: none"> • Competence framework describing the competences expected for roles within the service. • Training and development plan to show how staff will achieve and maintain competences
HP-204	Competences – All Health and Social Care Professionals			X		X	Competence Framework and Training Plan: <ul style="list-style-type: none"> • Competence framework describing the competences expected for roles within the service. Training and development plan to show how staff will achieve and maintain competences
HP-299	Administrative, Clerical and Data Collection Support	X		X			
HP-301	Support Services	X		X			
HP-302	Emergency Department – Staff Competences			X		X	Competence Framework and Training Plan: <ul style="list-style-type: none"> • Competence framework describing the competences expected for roles within the service. Training and development plan to show how staff will achieve and maintain competences
HP-303	Laboratory Service	X		X			
HP-304	Specialist Services	X		X			
HP-402	Facilities and Equipment		X				
HP-499	IT System		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	
HP-501	Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders			X	X	X	Relevant guideline
HP-502	Guidelines: Concentrate Use and Monitoring			X	X	X	Relevant guideline
HP-503	Clinical Guidelines			X	X	X	Relevant guideline
HP-504	Emergency Department Guidelines			X	X	X	Relevant guideline
HP-505	Guidelines on Care of Patients requiring Surgery			X	X	X	Relevant guideline
HP-595	Guidelines on Transition and Preparing for Adult Life			X		X	Relevant guideline
HP-599	Care of Vulnerable People			X		X	Guidelines: for the care of vulnerable adults. These may be Trust-wide guidelines
HP-601	Service Organisation			X		X	Copy of operational procedure
HP-602	Multi-Disciplinary Team Meetings			X		X	Documentation depends on local implementation for example minutes of meetings / evidence of attendance at meetings
HP-603	Multi-Disciplinary Clinics			X		X	Documentation depends on local implementation for example minutes of meetings / evidence of attendance at clinic
HP-604	Liaison with Other Services			X		X	Notes from relevant meetings
HP-701	Data Collection					X	Examples of data showing compliance with the QS
HP-702	Audit					X	Audit programme of plan. Examples of completed audits, action plans and monitoring
HP-706	Research	X		X		X	Examples of participation in research

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	
HP-798	Multi-disciplinary Review and Learning			X		X	Documentation depends on local arrangements, for examples minutes of meetings where review and learning is discussed.
HP-799	Document Control					X	Organisations document control policies and compliance determined from documentation presented.
HY-199	Involving Patients and Carers			X		X	Examples of changes made as a result of feedback
HY-203	Inherited and Acquired Bleeding Disorders Network Leads	X					
HY-204	Education and Training			X		X	Copy of training programme
HY-503	Guidelines			X	X	X	Copies of relevant guidelines
HY-701	Ongoing Monitoring			X		X	Copies of relevant data
HY-702	Audit			X		X	Copy of audit programme and completed audits
HY-703	Research			X		X	Examples of participation in research
HY-798	Network Review and Learning			X		X	Documentation depends on local arrangements, for examples minutes of meetings where review and learning is discussed.
HZ-601	Commissioning of Services			X		X	Service specifications
HZ-701	Clinical Quality Review Meetings					X	Documentation depends on local arrangements, for examples minutes of meetings where review and learning is discussed.
HZ-798	Network Review and Learning			X		X	Documentation depends on local arrangements, for examples minutes of meetings where review and learning is discussed.

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