CARE OF PEOPLE WITH INHERITED AND AQUIRED HAEMOPHILIA AND OTHER BLEEDING DISORDERS

Quality Standards v4.0

Reference number	Quality Standard	Notes	How Assessed
1	**Service Information** Written information should be offered to people with bleeding disorders (PwBD) and, where appropriate, their carers covering at least: 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. How to access physiotherapy and psychology f. Relevant national organisations and local support groups g. Where to go in an emergency and how to access out of hours services h. Information on delivery of products including company contact details. i. How to: i. Access social care and support services ii. Access benefits and immigration advice iii. Interpreter and advocacy services, PALS, spiritual support iv. Give feedback on the service, including how to make a complaint. v. Get involved in improving services (QS 10)	1. *Information should be written in clear, plain English and should be available in formats and languages appropriate to the needs of the PwBD, 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).* 2. *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 PwBD letters, then examples will need to be seen by reviewers.* 3. *Information should be up to date in all forms, the reviewers will check that websites/leaflets are up to date.* 4. *This QS is about signposting to relevant services. The actual services available may be different in different areas.*	Visit MP&S Doc
2	**Condition-Specific Information** Written and or online information should be available and offered to PwBD and, where appropriate, their carers covering: a. A description of their condition and how it might affect them # b. Problems, symptoms, and signs for which emergency advice should be sought. c. Genetics of inherited bleeding disorders d. Testing for carrier status and the implications of being a carrier. e. Treatment options including on demand, prophylaxis, home therapy and use of Haemtrack. f. How to manage bleeding at home g. Ports, fistulae, and in-dwelling access devices (if applicable) h. Approach to elective and emergency surgery	1. *As QS 1* 2. *Information may be localised, national leaflets or other sources where appropriate.* 3. *Information may be given at different stages of the PwBD pathway.* 4. *Information on women's health issues should cover, menorrhagia at least, contraception, pregnancy, childbirth.* 5. *Health promotion may not be relevant for all PwBD but leaflets from other services or evidence of signposting PwBD to other service in clinic letters would be sufficient evidence.* 6. *Travel advice information may cover the EUHANET locator of haemophilia services www.euhanet.org/centrelocator/ and the WFH travel tool as well as need for travel letter and how to get help when travelling.* 7. *Information on testing for carrier status and the implications of being a carrier should include arrangements for specialist referral.*	Visit MP&S Doc

	i. Women's health issues j. Dental care k. Travel advice l. Vaccination advice m. Health promotion to include to smoking cessation, healthy eating, weight management, exercise, alcohol use, sexual and reproductive health, and mental and emotional health and well-being. n. Sources of further advice and information # Condition specific information should be available covering: 1. Haemophilia A 2. Haemophilia B 3. Von Willebrand Disease 4. Acquired haemophilia 5. Inherited platelet disorders 6. Bleeding Disorder of unknown cause (BDUC) 7. Other less common and rare bleeding disorders	*8. Vaccination advice – route of vaccination rather than the recommendations about which vaccination required.*	
3	**Plan of Care** Each PwBD and, where appropriate, their carer should discuss and agree their Plan of Care that is age appropriate and should be offered a written record covering: a. Agreed goals, including lifestyle goals. b. Self-management c. Planned assessments, therapeutic and/or rehabilitation interventions. d. Early warning signs of problems, including acute exacerbations, and what to do if these occur. e. Agreed arrangements with school or other education provider. f. Planned review date and how to access a review more quickly, if necessary g. Who to contact with queries or for advice. The plan of care should be reviewed at each clinic appointment or at other times if clinically relevant.	*1. This QS is about a holistic view of the PwBD 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. This may be documented over a series of letters.* *2. Some PwBD may need additional detail in their Plan of Care, for example, people with learning disabilities or those who are resident in a care home.* *3. Planned therapeutic interventions include planned surgery as well as pharmacological and non-pharmacological therapies.* *4. Examples of school care plans should be seen.*	MP&S CNR

	The Plan of Care should be communicated to the PwBD GP and to relevant other services involved in their care.		
4	**Out-patient review of PwBD** A formal review of PwBD should take place regularly: For those with severe and moderate haemophilia, any PwBD on prophylaxis and other severe bleeding disorders at least twice a year. This may be more frequent in the paediatric setting based on clinical need. The following multi-disciplinary clinic arrangements for these PwBD should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability or clear referral pathway for social work and psychology staff For those with mild bleeding disorders the centre should have a documented follow up pathway with a plan for managing DNA and PIFU if used. These PwBD should have access to the full MDT if clinically required but may not be seen in a combined clinic. This review should involve the PwBD, where appropriate their carer the outcome of the review should be communicated in writing to the PwBD and their GP.	1. *This QS expects that in HCCCs these staff will be present together with the PwBD and their carers at the same time in order that a holistic approach to care can be discussed and agreed.* 2. *Other arrangements, such as video-links, may be appropriate so long as the aim of a patient-centred, holistic discussion is achieved.* 3. *A longer review duration may be appropriate in some conditions where there are specific clinical indications for specialist review at these times.* 4. *Centres will be asked to provide DNA rate, policy for managing DNA and evidence on how to manage DNA in those on prophylaxis.* 5. *If PIFU is used evidence of guideline/SOP/policy on who is suitable and how it was implemented.*	MP&S CNR
5	**Contact for Queries and Advice** Each PwBD 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.	1. *Centres will be asked how PwBD contact the service both in and outside usual working hours and how this information is communicated (leaflet, letter, website).* 2. *This 'advice line' may also provide an advisory service for general practitioners, dental practitioners and staff working in other health and social services.*	Visit MP&S
6	**Haemtrack (PwBD on Home Therapy)**	1. *Evidence may include clinic letters documenting use of Haemtrack, letters sent out to encourage use or other methods used by centres to encourage Haemtrack use.*	MP&S Visit Doc

	All PwBD on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack. Use should be documented in clinic letters/ plan of care.		
7	**Environment, Facilities and Equipment** The environment and facilities in out-patient clinics, wards and day units should be appropriate for the number of PwBD with inherited and acquired bleeding disorders and accessible by people with severe mobility problems. Facilities and equipment appropriate for the service provided should be available including: a. Fridges b. Storage c. Clinical rooms for staff of all disciplines to see PwBD and carers with adequate space for physiotherapy assessment. d. Room for multi-disciplinary discussion e. Room for educational work with PwBD and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all relevant clinical areas h. Access to adequate IT equipment with clinical systems All equipment should be appropriately checked and maintained.	1. *Required facilities and equipment are not strictly defined but should be appropriate for the usual number and case mix of PwBD cared for by the service.* 2. *Evidence of admissions of PwBD to other clinical areas may be used in determining compliance with this QS.*	Visit BI MP&S
8	**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	1. This QS applies only to services where significant numbers of young people transfer from paediatric services. The QS applies to both paediatric and adult services. 2. The 'Ready Steady Go' transition programme provides additional information on transition to adult services and preparation for adult life. 3. Arrangements should comply with national guidance for Looked After Children - Preparing for independence https://www.nice.org.uk/guidance/ph28 4. This standard may be evidenced with discussion in clinic letters, Ready Steady Go' documents or patient held notes. 5. Centres should have documented pathways agreed between relevant paediatric and adult services.	MP&S Visit Doc

	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 The Centre should have a guideline/SOP covering this information	6. Guidelines should cover the areas in the standard (this may be a trust guideline and not specific to haemophilia)	
9	**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.	1. Written information or clear sign-posting information should be available.	MP&S Visit
10	**Involving PwBD and Carers** The service should have: a. Mechanisms for receiving regular feedback from PwBD and carers about treatment and care they receive. b. Mechanisms for involving PwBD and carers in decisions about the organisation of the service. c. Examples of how the service has engaged PwBD / received feedback or made changes made as a result of feedback and involvement of PwBD and carers.	1. The arrangements for receiving feedback from PwBD and carers may involve surveys, including the national patient survey, focus groups and /or other arrangements. They may involve Trust-wide arrangements so long as issues relating to the specific service can be identified.	MP&S
11	**Leadership team** The leadership team will consist of a lead consultant and other members agreed at a local level. This may include nurse, physiotherapist and psychologist, clinical scientist, or other members of the MDT. The lead consultant will be responsible for staff training, guidelines and protocols,	1. This may be evidenced by a list of names, minutes from leadership or operational meetings and in discussion on the visit.	BI MP&S

	service organisation, governance and for liaison with other service but may delegate some of these roles to others in the leadership team. The leadership team should all be registered healthcare professional with appropriate specialist competences and should undertake regular clinical work with the service and have specific time allocated for their leadership role.		
12	**Staffing levels and skill mix** a. 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 PwBD cared for by the service and its role in the network. b. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. c. 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. d. 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: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours. ii. On-call consultant specialising in the care of people with inherited and acquired bleeding disorders 24/7 in HCCC. iii. On call haematology consultant with arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders in HC. b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7)	1. 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. 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: All qualified nursing staff regularly caring for PwBD with inherited bleeding disorders are expected to have completed the HNA "Introduction to Bleeding Disorders Course" All specialist nurses should have completed, the Contemporary Care Course (previously Essentials and/or Advancing Haemophilia Courses). A specialist inherited and acquired bleeding disorders nurse should be able to: a. assess PwBD. b. manage episodes of care and home treatment programmes c. refer PwBD to other healthcare professionals as necessary. d. teach PwBD, families and other hospital staff about inherited and acquired bleeding disorders and their treatment. e. evaluate outcomes.	BI MP&S Doc Visit

	ii. Ward, out-patient, and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Practitioner psychologist or appropriately trained psychotherapist with specialist knowledge in IBDs. e. Access to Specialist senior social worker f. Data manager g. Biomedical Scientist and/or Clinical Scientist (further detail on the requirements are included inQS 17)	Nursing competence should be assessed by using the UK Haemophilia specialist nurse: competencies fit for practice in the 21st Century https://onlinelibrary.wiley.com/doi/pdf/10.1111/hae.14002 Ongoing CPD should be in line with developing their competence for their own needs and the needs of the service. For example, HEE modules in Genetics/Genomics, NHSE modules in managing Pain or full qualification in Advanced Nurse Practice as described by HEE https://advanced-practice.hee.nhs.uk/ 4. Physiotherapy staff should follow the HCPA service standards for paediatrics and adults. For HC evidence for physio referral pathway and numbers of PwBD referred/ length of waiting list 5. Social worker – while it is advisable to have a dedicated social worker, a clear pathway of referral will be sufficient to meet this current standard based on current service specification. 6. Psychology staff: Specialist psychological support should be provided by a fully trained and accredited psychological practitioner (e.g., Clinical /Counselling/Health Psychologist) with specialist knowledge of Haemophilia and IBDs. There should be a named psychologist or psychologists with defined time in their job plane for direct provision of care for PwBD and supporting the wider team for indirectly supporting PwBD with their psychological needs. They must have sufficient skills to provide level 3-4 psychological care (in line with NICE guidance for palliative care service standards). They should be able to: a. Provide specialist screening and assessment for those with complex needs. b. Provide specialist intervention drawing on a range of evidence-based psychological models and with reference to relevant NICE guidelines. c. Provide specialist advice and supervision on psychological issues to MDT, where indicated. This can be achieved via attendance at MDT meetings and formal supervision and informal clinical discussions. d. Provide teaching and training to the MDT as required. e. Contribute to service level audit and evaluation.	

13	**Service Competencies and training plan** a. All staff to complete trust mandatory training including regular appraisal. b. All clinical staff to have CPD relevant to bleeding disorders. c. All new nurses/AHP/Psychologists to have opportunity to attend introduction to bleeding disorders course and the contemporary care course, provided by the Haemophilia Nurses Association d. All specialist clinical staff to have opportunity to attend national and/or international conferences and to develop subspecialist interests.	1. Mandatory training and appraisal can be demonstrated from trust reports, showing overall compliance, not individual staff. 2. CPD can be demonstrated as CPD certificate from royal college, in discussion at review. 3. Please see standard 12 for nursing CPD and competence	MP&S Doc
14	**Administrative, Clerical and Data Collection Support** Dedicated administrative, clerical and data collection support should be available.	1. 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.	BI MP&S
15	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: 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/podiatry	1. 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. 2. These services may be hospital or community-based so long as PwBD have access to services when at home and when admitted to hospital.	MP&S BI
16	**Emergency Department** Guidelines on management of PwBD in the Emergency Department should be in use. a. To include details of electronic alert visible in ED b. Who to contact for advice 24/7 ED medical and nursing staff should have training on inherited and acquired bleeding disorders.	1. This QS applies to Emergency Departments normally attended by people with inherited and acquired bleeding disorders. 2. This can be evidenced by records of teaching in ED, guidelines, and communication with ED. 3. Audit or survey results plus action taken	MP&S Doc

	ED pathway should be audited +/- PwBD survey on emergency attendance on annual basis.		
17	**Laboratory Service** a. A UKAS 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 25) regularly. c. The following tests should be available in a timely manner for the diagnosis and management of inherited bleeding disorders: i. All coagulation factor assays. ii. ii. Inhibitor screening iii. FVIII inhibitor quantification iv. VWF antigen v. VWF activity vi. Platelet function testing d. Pathway for referral to molecular Genetic Laboratory service for: i. detection of causative mutations in PwBD ii. carrier detection iii. discussion of results in genomics MDT when needed.		BI MP&S

18	**Specialist Services** Timely access to the following specialist staff and services should be available as part of a HCCC service where appropriate depending on whether adult, paediatric or all age service. HCs should be able to access these services through network arrangements: a. Obstetrics including reproductive counselling, information about pre-implantation genetic diagnosis and antenatal diagnosis. b. Foetal medicine c. Vascular access (consultant surgeon or interventional radiologist with experience of venous access devices) d. Orthopaedic surgery e. Care of older people services f. Dental services g. HIV services h. Hepatology i. Medical genetics (Genetic Counselling Services) j. Pain management services k. Rheumatology Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.	1. As QS 15 note 1. 2. Some of the above may not be applicable to children's IABD services.	BI MP&S
19	**IT System** IT systems should be in use for: a. Storage, retrieval, and transmission of PwBD information, including access to the latest treatment plan and vCJD status. b. PwBD administration, clinical records, and outcome information c. Data to support service improvement, audit, and revalidation	1. IT and records systems should be integrated to avoid duplicate entry of PwBD data. The ability to transmit data to the National Haemophilia Database without re-entry of data is therefore a requirement for this QS. 1. 2. This QS may be achieved through use of the Haemophilia Centre Information System (HCIS) or equivalent.	Visit
20	**Diagnosis Guidelines for People with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering the investigation and diagnosis of suspected bleeding disorders. The guidelines should cover. a. Haemophilia A	1. 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. 2. Guidelines should include: a. Genetic testing and genetic counselling	MP&S Doc

	b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia. e. Inherited platelet disorders f. Bleeding disorder of unknown cause g. Other less common and rare bleeding disorders h. haematological investigation of menorrhagia i. haematological investigation in child suspected of inflicted injury. j. non-specific bleeding disorders	b. Identification of potential carriers and offering genetic counselling and testing c. Version control on documents	
21	**Guidelines: Treatment and Monitoring of IABD** Guidelines should be in use covering: a. Factors concentrate and non-factor replacement therapy i. Initiation and monitoring of prophylaxis ii. Home therapy iii. Use of extended half-life products, including inhibitor testing and PK assessment. iv. Use of non-factor replacement therapy b. Management of factor concentrate and non-factor replacement therapy supplies including: i. Ordering ii. Storage iii. Stock control to ensure all stock is up to date and waste is minimised. iv. Prescription and delivery for PwBD on home treatment v. Arrangements for emergency 'out of hours' supply vi. Recording issue to PwBD vii. Recording use by PwBD, including on Haemtrack. viii. Submission of data via NHD for quarterly returns	1. Local adapted guideline with version control 2. Arrangements for management of factor concentrates may be network-wide or may be locally agreed.	MP&S Doc
22	**Clinical Guidelines/Pathways** The following clinical guidelines/pathways should be in use: a. Management of acute bleeding episodes, including PwBD with inhibitors b. Immune tolerance therapy c. Dental care	1. As QS 21 2. UKCHDO/BSH guidelines should be implemented wherever possible, if not it should be clear which are being followed. 3. HC guidelines should include indications for escalation to the HCCC and should be consistent with those in use in their linked HCCC. 4. Some of the above may not be applicable to children's IABD services.	MP&S Doc

	d. Care of PwBD with hepatitis C e. Care of PwBD with HIV f. Antenatal care, delivery, and care of the neonate g. Management of synovitis and target joints h. Long term surveillance of musculoskeletal health i. "For public health purposes": care of PwBD at risk of vCJD who are undergoing surgery.		
23	**Guidelines on Care of PwBD requiring Surgery.** Guidelines on the care of PwBD with inherited and acquired bleeding disorders who require surgery should be in use covering at least: a. Involvement of surgical and inherited and acquired bleeding disorders service in agreement of a written plan of care prior to, during and post-surgery b. Communication of the agreed plan of care to all staff involved in the PwBD 's care prior to, during and post-surgery. c. Documentation of care provided. d. Arrangements for escalation in the event of unexpected problems	1. As QS 21 2. Additional evidence of guideline uses e.g. specific proformas, examples of plans	Doc MP&S CNR
24	**Service Organisation** The service should have an operational procedure covering at least: a. Ensuring all children who are in-patients have a named consultant paediatrician and a named haematologist with expertise in caring for PwBD 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 PwBD. e. Arrangements for follow up of PwBD who 'do not attend'.	1. 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.	MP&S Doc Visit

	f. Arrangements for transfer of PwBD information when PwBD move areas temporarily or permanently. g. Ensuring PwBD ' plans of care are reviewed at least six monthly for those with severe haemophilia and at least annually for other PwBD (QS 3) h. Ensuring school visits for children with severe haemophilia at least at each change of school (children's services only) i. Ensuring PwBD are visited at home where clinically appropriate at least annually if they are unable to attend clinics, including those in nursing homes. j. Lone working		
25	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss PwBD ' plans of care including surgical procedures should take place regularly involving: a. All core members of the specialist team b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the PwBd care as part of network arrangements.	1. This QS can be shown with minutes or attendance register for MDT	Doc MP&S
26	**Multi-Disciplinary Clinics/Liaison Services** Combined clinics or other arrangements for multi-disciplinary discussion with a. orthopaedics and or rheumatology b. obstetrics and gynaecology c. paediatrics d. HIV e. Hepatology	1. Multi-disciplinary arrangements for discussion with some services may not be applicable to children's IABD services.	
27	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all PwBD b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism	1. 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.	

	c. Data required to complete the NHS E National Haemophilia Dashboard or other national mechanisms. d. Adverse events reported to NHD.		
28	**Research** The service should actively participate in research relating to the care of PwBd with bleeding disorders. The service should also offer links with other services to maximise research study opportunity. Staff members participating in research should be allocated appropriate time for this role.	1. A list of research participated in in the last three years and the number of PwBD recruited into research studies is appropriate documentary evidence of compliance with this QS.	
29	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Audit – the service must have an audit plan and it must include audit of emergency and out of hours care (QS 23) b. Positive feedback, complaints, outcomes, incidents and 'near misses' c. Morbidity and mortality d. Haemophilia Dashboard (when relevant) e. Review of UKHCDO Annual Report benchmarking information on concentrate use f. Ongoing reviews of service quality, safety, and efficiency g. f. Published scientific research and guidance.	1. Evidence for some of this QS may come from minutes of team, governance, and M&M meetings.	MP&S Doc
30	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures	1. Specific documentary evidence of compliance is not required. This QS will be determined from the other documentary information provided. 2. Copies of the organisations document control policies are also required for compliance with this QS	Doc

'How assessed' key	
BI	Background information supplied to the review team
Visit	Visiting facilities
MP&S	Meeting patients, carers, and staff
CNR	Case notes review or clinical observation
Doc	Documentation should be available. Documentation may be in the form of a website or other social media.

Commissioning

The peer review is not a review of the commissioners however we are keen to know how each centre engages with the commissioning team as this is vital in the way a service is able to make improvements.

Who is your commissioner?

How is your service funded? – block contract, per clinic attendance, other?

Do you meet with them to discuss?

a. contracts
b. finance – including increase in work and additional requirements.
c. review of service and how meeting peer review standards
d. achievements and challenges for the service

Networks

These are a set of exploratory and explanatory standards as there is no clear definition of networks within the current service specification. They will not be assessed as met/unmet, but the reviewers will review the information, discuss with staff and include information and areas of excellence or areas requiring development in the final report.

Do you consider your centre to be part of a network (this includes all types of networks – informal, hub and spoke, formal network)?

Please describe the structure of your network.

a. Do you have a network leadership team? Lead consultant and deputy
b. Lead specialist nurse
c. Lead physiotherapist
d. Lead clinical or counselling psychologist.
e. Lead manager

Do you have a network MDT?

Do you have a network programme of education and training? Please describe how this helps comply with QS 12 and QS 29 for staff across the network.

Guidelines

Do you have network guidelines covering:

a. Diagnosis for people with suspected inherited and acquired bleeding disorders (QS 20)
b. Concentrate use and monitoring (QS 21)
c. Clinical guidelines (QS 22)
d. Management of PwBD in the Emergency Department (QS 16)
e. Care of PwBD requiring surgery (QS 23)
f. Transition and preparing for adult life (QS 08)

PwBD and carer engagement

Do you have a mechanism for involving PwBD and carers from all services in the work of the network? Please describe and give examples.

Data and Audit

Do you have network wide audits? Please describe. Please describe how data is collected in the network, how factor concentrate use and bleeds are reviewed.

Network Review and Learning

Please describe how you review the following:

a. Identify any changes needed to network-wide policies, procedures and guidelines.

b. Review results of audits undertaken and agree action plans.

c. Review and agree learning from positive feedback, complaints, critical incidents and 'near misses', including those involving liaison between teams.

d. Share good practice and potential service improvements