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

Birmingham Women's and Children's NHS Foundation Trust

Visit Date: 10th June 2019

Report Date: October 2019

8831

Contents

Introduction

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Birmingham Women's and Children's NHS Foundation Trust, which took place on 10th June 2019.

The purpose of the visit was to review compliance with the Quality Standards for Inherited and Acquired Haemophilia and other Bleeding Disorders (V1 July 2018), which were developed by the UK Haemophilia Centres Doctors' Organisation (UKHCDO) Peer Review Working Group working with the Quality Review Service (QRS).

The peer review visit was organised by QRS on behalf of the UKHCDO.

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care, which can be used as part of organisations' Quality Accounts and Annual Governance Statement. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit.

Appendix 1 lists the visiting team and **Appendix 2** gives details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- Birmingham Women's and Children's NHS Foundation Trust
- NHSE Specialised Commissioning West Midlands

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place, for monitoring their implementation and for liaising, as appropriate, with other commissioners.

Acknowledgements

We would like to thank the team at the Birmingham Women's and Children's NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the parents and patients who took time to meet the review team.

Thanks are also due to the visiting team (**Appendix 1**) and their employing organisations for the time and expertise they contributed to this review.

About the Quality Review Service

QRS is a collaborative venture by NHS organisations to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews (often through peer review visits), producing comparative information on the quality of services and providing development and learning for all involved.

More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Return to Index

Birmingham Women's and Children's NHS Foundation Trust

Birmingham Women's and Children's NHS Foundation Trust was one of the largest dedicated children's hospital trusts in the UK. Situated in the centre of England, the Trust provided acute and tertiary specialist services for 1.2 million children in the West Midlands. The Comprehensive Care Centre provided a range of services relevant to children with bleeding disorders, including surgery, dental care, intensive care and clinical genetics.

Haemophilia services were integrated within the haematology / oncology department which managed children with both malignant and non-malignant diagnoses. Outpatient and day case care was provided in a large purpose-built facility, created in 2018, which had improved the previous facilities for patients. If admission was required, inpatient facilities were provided on the Haematology–Oncology ward (Ward 18). Depending on clinical need, patients could be admitted to another ward such as surgery or Ear, Nose and Throat (ENT), if appropriate.

A comprehensive diagnostic service was available to investigate children with potential bleeding disorders aged 0 to 16 years, with assays available around the clock from the on-site haematology laboratory. Children with bleeding disorders were under the care of the two consultants, one of whom was also the Centre director. The consultants co-ordinated diagnosis and management with the haemophilia Advanced Nurse Practitioner (ANP) and specialist haemophilia nurses. At the time of the visit, close to four hundred children with congenital bleeding disorders were registered at the Centre. Approximately one hundred children had severe and moderate haemophilia A and B. In addition, there were several children registered with other severe bleeding disorders. All severely affected children were reviewed at least every six months in the consultant-led clinic. All children with severe and moderate haemophilia A and B were seen annually in a multi-disciplinary clinic by a haematologist, a dentist and a physiotherapist. Haemophilia joint score assessment was also performed in these clinics. Home delivery of factor concentrate was organised for those on prophylaxis. Comprehensive care was available for all patients, including those with inhibitors. Children with milder disorders were usually followed up annually.

All registered children had open access to the haemophilia unit. This was open between 9am and 4.30pm. Outside these hours, and at weekends, patients attended the Emergency Department (ED). Each child had an individualised care treatment plan, and the family and the ED had a paper copy of this. The plan was also available on the hospital patient correspondence system. Management of the patient was discussed with the on-call consultant haematologist. All junior doctors in the hospital, including in the ED, were trained in the management of children with bleeding disorders as part of their Trust induction.

Children remained under the care of Birmingham Children's Hospital (BCH) until the age of sixteen, when they were transitioned to the neighbouring adult haemophilia centre at University Hospital Birmingham (UHB). UHB had quarterly new patient clinics especially for transitioned patients. These patients were offered a visit to UHB prior to transition. The children's hospital data team liaised with the UHB team to ensure that patients were seen at UHB and that home delivery from UHB was in place.

All carrier mothers were seen in a joint haematology / obstetric clinic. BCH also received a copy of the birth plan. Any new, severe bleeding disorder neonate was seen at BCH within a week after discharge from Birmingham Women's Hospital (BWH).

The table below summarises the conditions and severity of children registered with the Centre at the time of the review:

Condition	Number of patients Total - 393	Number of patients who had an annual review in last year Total - 282	Number of inpatient admissions in last year Total - 45
Haemophilia A	102 Severe: 70 Moderate: 8 Mild: 24	99. 3 new referrals seen on haemophilia unit by consultant, due formal clinic later	18
Haemophilia B	23 Severe: 10 Moderate: 5 Mild: 8	22	4
Von Willebrand	80 Severe: 27 Mild: 53	56	11
Other	188	105	12

Note: All children with haemophilia A and haemophilia B had a face-to-face review (usually 3-6 monthly) either at BCH or at a shared care outreach clinic. Other patients with severe bleeding disorders, such as Glanzmann's thrombasthenia and Bernard–Soulier Syndrome, were also seen every 3-6 months, depending on severity.

Examples of the other severe bleeding disorders registered at the Centre were:

Diagnosis	Number
Glanzmann's thrombasthenia	7
Type 3 VWD	4
Severe Factor V deficiency	3
Severe Factor VII deficiency with inhibitors	1
Severe Factor XIII deficiency	2
Bernard–Soulier Syndrome	3

Emergency Care

Parents were given contact numbers for the haemophilia unit as the first point of contact for problems in routine working hours. All registered children had open access to the haemophilia unit, which was open between 9am and 4.30pm. Outside these hours, and at weekends, patients attended the Emergency Department (ED). Each child had an individualised treatment plan, and the family and ED team had a paper copy of this. The record was also available on the hospital patient correspondence system. Records were updated at clinic. The management of each patient was discussed with the on-call consultant haematologist. All junior doctors in the hospital, including those in the ED, had training in management of children with bleeding disorders as part of their Trust induction. There was an alert on the hospital patient information system for children with bleeding disorders.

Ward Care

Twenty-five beds were available (eight in bays and seventeen in cubicles). Access to these beds was shared between haematology and oncology patients. Access was also available to beds on the general paediatric wards and surgical ward if patients were admitted for surgical procedures. Patients remained under the care of the paediatric haematology team.

Day Unit Care

Patients were seen in a purpose-built outpatient and haemophilia unit for the exclusive use of children with bleeding disorders. This was adjacent to the haemoglobinopathy unit, the stem cell transplant unit and the haematology / oncology day care unit. There was a large waiting area, with toys and activities available, and an adolescent area. There were several consulting rooms and individual rooms for phlebotomy, counselling and administration of treatment, and a large day care area with reclining chairs.

Outpatient Care

There were several consulting rooms available next to the haemophilia unit. Weekly clinics were also held in these consulting rooms. Multi-disciplinary clinics were held in the dental department, within the main outpatients area.

Community-based Care

The specialist haemophilia nurses organised home visits as and when required. They also liaised with the haemophilia nursing teams in the shared care hospitals for other treatments such as portacath® access and venepuncture.

Return to Index

Review Visit Findings

Achievements

This was an excellent, safe service with committed and dedicated staff in all professional groups who were working resourcefully to meet the needs of children and families despite the under-provision of staff in some staff groups. Dental specialists worked as an integrated part of the multi-disciplinary team, and support from the laboratory was strong. The data management staff were key team members. The team worked in a collaborative and supportive manner with other paediatric haematology sub-specialty teams. The specialist team was well supported by clinical and non-clinical managers.

Patient feedback was overwhelmingly positive. The Centre director had received a trust 'Moment of Magic', which was an award based on nominations from patients and families. Parents reported that support for the wider family as well as the individual patient was good, and that they felt able to raise concerns freely with any member of the team. They explained that they felt that all their needs were met. Some families chose to attend this Centre rather one closer to their home because of their confidence in the quality of the care they received here.

The haemophilia unit was housed in a newly refurbished hospital building, which was spacious, bright and colourful. As part of a very large and eminent children's hospital, the team was able to access all the specialist support they needed to provide for their patients.

Good Practice

1 The child's care plan was available electronically and also as a hard copy in the ED. In addition, parents had a copy, which gave them confidence when attending the ED out of hours.

2 Parents had letters to give to ambulance staff in the event of an emergency, outlining the child's condition and management.

3 The form of a letter to be written to parents after diagnosis and the first consultation was comprehensive and clear, and reviewers noted that this was an excellent start to reassuring and empowering families.

4 Many documents supporting the service were excellent, including the diagnostic guidelines, ED guidelines, and several of the clinical guidelines, including that on the management of target joints. A 'home delivery alert' was noted to be very useful.

5 Trust-wide practice and guidance for the transition of young people from paediatric to adult services, and for safeguarding, were excellent.

6 Immunisation clinics established by the specialist nurses were innovative and were welcomed by families, as GPs are often concerned about giving injections to infants with bleeding disorders.

7 Ready support from radiology in offering rapid ultrasound scanning to assess possible joint bleeds was notable.

8 Gynaecologists attending from Heartlands Hospital offered on-site clinic appointments for teenagers with bleeding disorders.

9 Staffing shortages made school visits difficult, and the team had established teaching sessions for school staff on site to try to mitigate this.

10 Team members had made extra efforts to address the needs of a teenage boy with a severe bleeding disorder and complicating mental health disorders.

11 Parking near the Centre was readily available, at discounted rates.

12 Document control for guidelines and policies supporting the service was good.

Immediate Risks: No immediate risks were identified at the time of the visit.

Concerns

1. **Staffing**

   Staffing provision in a number of professional groups was judged to be insufficient.

   a. **Nursing**. There had been a recent reduction from three to two specialist nurses. Based on the current complement, the nurses did not have capacity to undertake some of the expected duties, including attending the multi-disciplinary clinics for the review of moderately and severely affected children. Nurses were seldom able to undertake school or home visits. There were no nurse-led clinics, which are often in place to help manage children with milder disorders and reduce the need for clinic visits.

   b. **Medical**. The Centre director and a supporting consultant colleague each had two Programmed Activities (PAs) in their job plan for their work in the bleeding disorders service. This was a reduction from a total of 14 PAs and resulted from the retirement of a senior colleague approximately one year previously. A business plan for an additional colleague to contribute a further six PAs had been submitted and this, if the position was approved and appointed to, would help with the shortfall.

   c. **Psychology**. There was no named psychologist member of the team, and no psychologist was available to see children and families at multi-disciplinary team clinic visits. Reviewers heard that families and children with severe and moderate haemophilia were assessed, via a questionnaire, as to the possible need for a referral. Additionally, when there were concerns about an individual or a family, referrals could be made to the general hospital service. However, it was noted that some less pressing needs for psychological intervention and support could be unmet, and the team were not able to access clinical supervision or regular case consultation.

   d. **Physiotherapy**. At the time of the visit, two named physiotherapists were working in the service but were currently funded at 0.2 WTE (combined total) for this service, which limited the support that they could provide to patients. Although they provided support for multi-disciplinary reviews, and recorded Haemophilia Joint Health Scores (HJHS), any unplanned attendances at the haemophilia centre for joint bleeds were assessed instead by a physiotherapist from the inpatient orthopaedic team when bleeped. These physiotherapists were responsive and engaged but were not able to provide ongoing care for children with joint bleeds, and inpatient children were managed instead by the general ward physiotherapy team. There was no direct access for families to advice and guidance if they were concerned about joint symptoms. There was also insufficient time to provide education to patients and families. It was understood that approval had been granted to appoint to a total of 0.8 WTE dedicated to the service, which would be more appropriate for this size of centre.

2. **Fridge**

   A fridge holding factor concentrates, located in a clinical area in the unit, was unlocked so that there was no control over who could gain access.[1]

[1] The Centre has confirmed that the fridges are always locked. However, on the day of the review, it was unlocked due to stocktaking and stock rotation.

Further Consideration

1 There had previously been out-of-hours direct access to Ward 15 for children, and Ward 15 had been located just above the ED. After the unit's move to the new location within the hospital, which was much further away from the ED, it had been agreed that children needed to present directly to the ED. Parents described being less confident of the care they received in the ED, and said that there could be delays in triage and treatment. An audit of times from presentation to treatment would be valuable, with further training for ED staff if necessary.

2 Some of the written standard operating procedures (SOPs) were found to be confusing, and it would be useful if these were revised. Three different SOPs, outlining different aspects of factor dispensing, were all entitled 'Dispensing of Factor Concentrates'. A SOP describing provision of factor suggested that the pharmacy needed to be involved on each occasion, rather than just at the initial prescription (which was the case in practice). The content of a guideline for managing a newly identified inhibitor was judged not to be in a form that would be practically useful.

3 The operational policy, and a guideline for daytime treatment on the haemophilia unit, were comprehensive and lengthy, and could usefully be indexed to aid readers in finding the section of guidance they were looking for.

4 Families could make contact with the team by phone, but not by e-mail. There was discussion about how parents at other centres find e-mail contact to be useful, especially as they can attach photos of a child's joint or minor injury if they are uncertain about severity. Getting advice without the need to bring the child in for assessment could be beneficial for some families.

5 The individual who held the nursing post that was vacant at the time of the review had been the transition lead. Transition planning and practice had therefore become less well-organised since her departure. It was observed that some more proactive planning for transition would be valuable.

6 There was a full audit plan in place, and data from some recent audits were made available to reviewers. However, *'conclusion with suggested actions arising'* was only available for one audit – immune tolerance induction. The findings would be more useful if the audits were all fully evaluated in this way.

7 Network meetings took place quarterly and were hosted by an engaged specialist commissioner. There was no lead psychologist or physiotherapist for the group, and consideration might be given to appointing to these lead roles to ensure balance in discussions and to promote the involvement and progression of senior professionals in these groups.

8 The agendas and minutes of the network meetings indicated that they were not used as opportunities for review and learning. Inclusion of audits, case discussions, and morbidity and mortality reviews could enhance the value of the meetings.

9 Data from linked haemophilia centres at Telford, Coventry and Stoke were submitted independently of the Comprehensive Care Centre (CCC). The commissioner noted that reporting had been inconsistent from these sites. Consideration could be given to managing all data reporting for the network through the CCC team, although additional resource might be needed to support this.

Return to Index

APPENDIX 1 Membership of Visiting Team

Visiting Team		
Dr Laura Baker	Clinical Psychologist Paediatric and Teenage and Young Adult (TYA) Oncology and Haematology	University Hospitals Bristol NHS Foundation Trust
Marie Eales	Paediatric Haemophilia Nurse	Oxford University Hospitals NHS Foundation Trust
Gemma Gardner	Patient representative	
Nicola Hubert	Paediatric Physiotherapist	Great Ormond Street Hospital for Children NHS Foundation Trust
Dr Sabiha Kausar	Paediatric Haematology Consultant	Manchester University NHS Foundation Trust

QRS Team		
Dr Anne Yardumian	Consultant Haematologist	Programme Clinical Lead
Rachael Blackburn	Assistant Director	Quality Review Service

Return to Index

APPENDIX 2 Compliance with the Quality Standards

Analyses of percentage compliance with the Quality Standards should be viewed with caution, as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but', where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Details of compliance with individual Quality Standards can be found below.

	Number of applicable QS	Number of QS met	% met
Comprehensive Care	37	33	89
Network	8	3	38
Commissioning	3	1	33
Total	48	37	77

Return to Index

Haemophilia Comprehensive Care Centres

Ref	Standard	Met?	Comments
HP-101	**Service Information** Written information should be offered to patients 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. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: 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)	Y	

Ref	Standard	Met?	Comments
HP-102	**Condition-Specific Information** Written information should be offered to patients and, where appropriate, their carers covering at least: 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 Information should be available covering: 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	Y	See Good Practice section of main report regarding the ambulance letter and the detailed letter given to patients following diagnosis.

Ref	Standard	Met?	Comments
HP-103	**Plan of Care** 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: a. Agreed goals, including life-style 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 and preparation for adult life (children and young people only) 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 communicated to the patient's GP and to relevant other services involved in their care.	Y	
HP-104	**Review of Plan of Care** 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.	Y	
HP-105	**Contact for Queries and Advice** 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.	Y	
HP-106	**Haemtrack (Patients on Home Therapy)** All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack.	Y	

Ref	Standard	Met?	Comments
HP-194	**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.	Y	
HP-195	**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	Y	
HP-198	**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	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	

Ref	Standard	Met?	Comments
HP-201	**Lead Consultant and Lead Nurse** 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.	Y	
HP-202	**Staffing Levels and Skill Mix** 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: 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 haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) 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. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	N	See Concerns section of main report regarding consultant PAs, psychology input and the capacity of the nursing team.

Ref	Standard	Met?	Comments
HP-203	**Service Competences and Training Plan** 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.	N	Reviewers saw lists of training that could be attended, but these were not populated for each member of the team to show what had actually been completed.
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: 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	Y	
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	
HP-301	**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	Y	
HP-302	**Emergency Department – Staff Competences** 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: 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	Y	

Ref	Standard	Met?	Comments
HP-303	**Laboratory Service** 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: 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: i. detection of causative mutations in patients with inherited bleeding disorders ii. carrier detection	Y	
HP-304	**Specialist Services** 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: 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.	Y	

Ref	Standard	Met?	Comments
HP-402	**Facilities and Equipment** 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 patients and carers d. Room for multi-disciplinary discussion e. Room for educational work with patients and carers f. Office space for staff g. Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas All equipment should be appropriately checked and maintained.	Y	However, see Concerns section of main report regarding an open fridge during stock taking and rotation.
HP-499	**IT System** IT systems should be in use for: a. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree b. Patient administration, clinical records and outcome information c. Data to support service improvement, audit and revalidation d. Alerting the specialist team when patients attend the Emergency Department	Y	
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	

Ref	Standard	Met?	Comments
HP-502	**Guidelines: Concentrate Use and Monitoring** Guidelines should be in use covering: a. Concentrate therapy: 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: 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	Y	
HP-503	**Clinical Guidelines** The following clinical guidelines should be in use: 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	Y	
HP-504	**Emergency Department Guidelines** Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.	Y	

Ref	Standard	Met?	Comments
HP-505	**Guidelines on Care of Patients requiring Surgery** Guidelines on the care of patients 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 patient's care prior to, during and post-surgery c. Documentation of care provided d. Arrangements for escalation in the event of unexpected problems	Y	
HP-595	**Guidelines on Transition and Preparing for Adult Life** Guidelines on transition of young people from paediatric to adult services should be in use covering at least: a. Taking responsibility for their own care b. Involvement of the young person and, where appropriate, their carer in planning the transfer of care c. Joint meeting between paediatric and adult services in order to plan the transfer d. Allocation of a named coordinator for the transfer of care e. A preparation period prior to transfer f. Arrangements for monitoring during the time immediately after transfer g. 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 the young person's new GP	Y	However, reviewers heard that because of recent changes in the nursing team that there was no designated transition lead at the time of the visit.
HP-599	**Care of Vulnerable People** Guidelines for the care of vulnerable children, young people and adults should be in use including: 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	Y	

Ref	Standard	Met?	Comments
HP-601	**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 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	Y	
HP-602	**Multi-Disciplinary Team Meetings** Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving: 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	Y	

Ref	Standard	Met?	Comments
HP-603	**Multi-Disciplinary Clinics** The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place: a. Involvement of medical, specialist nursing and physiotherapy staff in clinics b. Availability of social work and psychology staff in clinics c. Combined clinics or other arrangements for multi-disciplinary discussion with: i. orthopaedics ii. rheumatology iii. obstetrics and gynaecology iv. paediatrics v. dental vi. HIV / hepatology	N	Reviewers heard that, although nurses did see children and families after appointments, for blood tests, stock rotation / return / general catch up, etc., the nurses were not physically present in the consultation rooms for the clinic. In addition, there was no input from a psychologist at the clinic (see HP-202).
HP-604	**Liaison with Other Services** Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.	N	Reviewers agreed with the Centre's self-assessment: regular meetings were held with the laboratory, the genetics team, the adult haemophilia centre, a dentist and a physiotherapist but not with other specialist services.
HP-701	**Data Collection** The following data should be collected: a. UK National Haemophilia Database data on all patients b. Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism c. Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms	Y	
HP-702	**Audit** The services should have a rolling programme of audit covering at least: a. Clinical guidelines (QS HP-503) b. Emergency and out of hours care (QS HP-504) c. Initiation of prophylaxis in children d. Inhibitor surveillance and Immune Tolerance Induction (ITI) e. Clinical reviews including joint scores (QS HP-103 & 104) f. Concentrate use and wastage	Y	
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	There was evidence of a research portfolio, but this was limited because of the current capacity of MDT members.

Ref	Standard	Met?	Comments
HP-798	**Multi-disciplinary Review and Learning** The service should have multi-disciplinary arrangements for review of and implementing learning from: a. Positive feedback, complaints, outcomes, incidents and 'near misses' b. Morbidity and mortality c. Haemophilia Dashboard d. Review of UKHCDO Annual Report benchmarking information on concentrate use e. Ongoing reviews of service quality, safety and efficiency f. Published scientific research and guidance	Y	
HP-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

Return to Index

Network

Ref	Standard	Met?	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Although there was evidence of regular West Midlands network meetings, reviewers did not see evidence of cross-network patient feedback being collated and discussed.
HY-203	**Inherited and Acquired Bleeding Disorders Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse c. Lead physiotherapist d. Lead clinical or counselling psychologist e. Lead manager	N	There was a named consultant and nurse lead, but no leads had been identified for other members of the MDT.
HY-204	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	Y	
HY-503	**Guidelines** Network guidelines should have been agreed covering: a. Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) b. Concentrate use and monitoring (QS HP-502) c. Clinical guidelines (QS HP-503) d. Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) e. Care of patients requiring surgery (QS HP-505) f. Transition and preparing for adult life (QS HP-595)	Y	
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) b. Network-wide data on concentrate use and bleeds	Y	
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers did not see evidence of an agreed network-wide audit programme.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders b. A list of research trials available to all patients within the network.	N	Reviewers did not see evidence of a network research policy or a list of agreed research activities across the network.

Ref	Standard	Met?	Comments
HY-798	**Network Review and Learning** Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to: 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	N	Although there was evidence of regular West Midlands network meetings, reviewers did not see evidence of discussions relating to review and learning from incidents, audits, policies etc.

Return to Index

Commissioning

Ref	Standard	Met?	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks including: a. Designated Comprehensive Care Centres and Haemophilia Centres and the relationships between them b. Whether the service cares for children, adults or both c. Referral pattern to each service, taking into account the type of patients who will be treated by each team	Y	
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, including achievement of QS HP-701 b. Each network, including achievement of QS HY-701 and QS HY-798 c. Service and network achievement of relevant QSs	N	Reviewers did not see evidence for the requirements of this standard.
HZ-798	**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.	N	Reviewers did not see evidence for the requirements of this standard.

Return to Index