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

University Hospitals Plymouth NHS Trust

Visit Date: 12th September 2019

Report Date: November 2019

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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 University Hospitals Plymouth NHS Trust, which took place on the 12th September 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:

- University Hospitals Plymouth NHS Trust
- NHS England Specialised Commissioning South West

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 and for monitoring their implementation, liaising, as appropriate, with other commissioners.

About the Quality Review Service

QRS is a collaborative venture between 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.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Acknowledgments

Quality Review Service would like to thank the staff of the Plymouth Haemophilia Centre 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 patients and carers 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.

Plymouth Haemophilia Centre

The haematology department at University Hospitals Plymouth comprised three haematologists with designated expertise in haemostasis. There were 4.5 other Whole-time Equivalent (WTE) senior haematologists who were also available to review patients out of hours.

There was one very experienced part-time (0.15 WTE) Clinical Nurse Specialist (CNS) designated to provide care for patients with bleeding disorders.

A designated senior physiotherapist provided cover and joint reviews for patients with severe haemophilia throughout the year.

Colleagues from the Bristol Children's Hospital NHS Foundation Trust provided outreach review and management of paediatric patients with severe and moderate haemophilia. At the time of the review, this took place every six months in the paediatric outpatient department.

The blood transfusion department stored all of the factor products, and these were available to the haematology consultants and Specialist Registrars and, on specific instruction, to other clinicians. Home delivery of factor products was provided locally. For children under 17, this role was picked up by the outreach team from Bristol.

There was an extensive haematology, and specifically haemostasis, laboratory providing cover 24/7 and offering all factor assays and other specialist haemostasis investigations such as platelet function.

Adult patients with bleeding disorders were reviewed at the Eden Unit. Patients with severe and some moderate haemophilia were reviewed every six months in a designated clinic at which they were also seen by a physiotherapist.

At the time of the review, the following numbers of patients were registered at the Centre:

Condition		Number of patients	Number of patients who had an annual review in last year	Number of inpatient admissions in last year
Haemophilia A	Adults	Severe = 9 Moderate = 2 Mild = 17	10	2
	Children	Severe = 8 Moderate = 2 Mild = 3	10	19
Haemophilia B	Adults	Severe = 0 Moderate = 0 Mild = 4	2	0
	Children	0		
Von Willebrand	Adults	140	40	
	Children	18	8	
Other	Adults	39	10	
	Children	0		

Emergency Care

During normal working hours (between 8am and 6.30pm), adult patients with bleeding disorders were advised to telephone the haematology day unit, with the intention that they would be reviewed there if they had non-serious injuries and concerns related to their bleeding disorder. Children and their families were advised to attend the Children's Decision Unit (CDU) at any time throughout the day, having informed either the haematology on-call team or one of the senior haemostasis clinicians. Occasionally these patients contacted the CDU directly. Adults were initially reviewed by the day unit Specialist Registrar (SpR), who would inform one of the haemostasis consultants. Paediatric patients were reviewed either by a senior haemostasis doctor or by the admitting paediatric team. Generally, one of the haemostasis team reviewed the patient on the CDU.

For emergencies and out of hours, adult patients were advised to attend the Emergency Department (ED). They would generally be reviewed by the on-call senior haematologist or one of the three haemostasis consultants. If this was not appropriate, one of the senior haematology trainees reviewed the patient either before or after triage in the ED.

Ward Care

At the time of the review, there were sixteen designated haematology beds on the Bracken Unit. An additional six beds were available on Brent Ward.

Day Care

A large day unit was used for the review of adult patients who did not have bleeds that threatened life or limb. This was open between 8am and 7pm.

Outpatient Care

Outpatient review for all adult patients took place in the Eden Unit, which was shared with the immunologists. There were four clinic rooms. The physiotherapist attended the reviews of severe haemophilia patients to complete joint scores and assess joints.

Community Based Care

Home delivery of factor was available for all patients who wanted it. The team also completed educational visits to new schools attended by young patients with bleeding disorders.

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Review Findings

Achievements

This was a long-serving, dedicated, and hardworking team providing a good service for adults and children. The adult service was dependent on the medical and nursing leads, whose time was taken up delivering the clinical service, with little spare time to work on service developments (see Concern below). The laboratory service was strong; a clinical scientist had recently been appointed, and the team worked closely with clinical colleagues to offer all the support needed by the service. The Centre team was well supported by colleagues in other specialties, by clinical and non-clinical managers, and by a quality team who were very involved in the service.

The facilities from which care was offered to adults and children were of a high quality, being light, spacious, and age appropriate.

Patients were wholehearted in their appreciation of the care they received from the core team and of the hard work they saw being invested to give them personalised and sensitive treatment.

The Bristol paediatric network had well-established links with Plymouth; twice-yearly outreach clinics by the Bristol Comprehensive Care Centre team were attended by the Plymouth haemophilia lead, paediatrician and nurse specialist. There were shared clinical guidelines, and the Bristol team prescribed and managed home delivery factor supplies for children. At the time of the review visit, shared educational and business meetings were planned.

Good Practice

1. The team had established separate dedicated haemostasis clinics, run from the Eden Unit, and separated from haematology-oncology and general haematology clinics. This improved patient experience and the move should be supported and maintained.
2. Within her limited working hours for the service (0.15 WTE, equating to just under six hours per week), the Clinical Nurse Specialist (CNS) had maximised liaison with other non-specialist nurses, especially in the paediatric department, to enable them to manage children presenting with acute joint bleeds if she was not available.
3. The Haematology Southern Network meetings, attended by nurses from all haematology sub-specialties, provided some peer support for the nurse specialist, pending bleeding disorder network meetings being established.
4. An outline ‘audit calendar’ and detailed staff training matrix had been drawn up, which once completed will allow for excellent clear recording of these activities.
5. A leaflet on inherited platelet disorders, developed by the CNS, was clear and useful.
6. There was a thermal monitoring system activated via WiFi for temperatures in the factor storage fridges in the blood bank. If temperatures went out of range, team members were automatically alerted by e-mail and the switchboard was also informed.
7. Document control for guidelines and policies was good. ‘Q-pulse’ quality management software was used, and most documents seen had clear dates of production, authorship, and review dates.

Immediate Risks

1. Some details in written clinical guidelines were lacking, or potentially confusing or misleading; in four instances these were judged to present a possible risk to patients:
    a. In the management of acute joint bleeds, it was not stated that for patients receiving Emicizumab, Feiba is contraindicated, as in combination these agents can lead to thrombotic microangiopathy and venous thrombosis. These patients should instead receive NovoSeven.

b. In a guideline on the treatment of von Willebrand Disease, the dosing instructions for Voncento were not clear. This contains both factor VIII and von Willebrand's factor [RiCof]. The guideline needs to be clear about which component is being used for the body weight-related dosage instruction. This is because there is a more than two-fold difference in the concentration of the two in the product.

c. The guideline on antenatal care, genetic testing and delivery did not include the need to undertake fetal gender testing at 9/40 (nine weeks' gestation). It also suggested undertaking chorionic villus biopsy [CVS] or cordocentesis at 20/40; CVS should be undertaken at approximately 11/40. Additionally, cordocentesis is seldom undertaken for pre-natal diagnosis of these disorders.

d. The same treatment guidance included the use of DDAVP but did not specify that this was only useful in some patients with haemophilia A, but not patients with haemophilia B or other conditions.

Trust Response: In relation to points a and b, these corrections were made on the day of the review, immediately following the closing meeting and were ratified at our general haematology MDT on Friday 13th September, as Version 2 of the document. The clinical guideline document was issued to the haematology team and Trust document library and evidence provided to the review team leaders.

In relation to points c and d, these corrections were made on Tuesday 24th September 2019, due to annual leave absence of core team members, when your letter was received. The clinical guideline document is now Version 3. This was provided to QRS on Tuesday 24th September 2019 and will be ratified at our general haematology MDT on Friday 27th September 2019, when it will be issued to the entire haematology team and published on the Trusts document library.

QRS response: We have received the evidence you supplied with the clinicians on the visit. I can confirm that once the changes are fully implemented, as described in your letter, this will fully address the immediate risks identified.

Concerns

1. **Staffing**

Staffing levels in almost all professional groups gave cause for concern. At the current levels, it was not possible to offer holistic multi-professional care, and there was insufficient protected time for medical and nursing staff to keep abreast of new and emerging treatments and to ensure patients were fully informed about all treatment options.

a. Specialist nursing staff: One named nurse was in post (0.15 WTE, equating to just over six hours per week). This nurse covered both adult and paediatric services, and there was no specific cover for her absence. Within her allotted time, she was home-visiting and supporting families of affected new-borns, leading on the transition process for children and young people moving over to adult services, and managing home care factor replacement prescriptions and ordering. She was seldom able to visit other patients at home, and other roles such as liaising with Emergency Department staff were also suffering. There was no named paediatric nurse specialist.

b. Senior medical staff: It was noted that, for adults, the Centre was essentially functioning as a 'Comprehensive Care Centre'. Although the Centre director felt that he could contact Bristol CCC colleagues if he had need of clinical advice at any time, the Bristol network had not yet extended to include adult patients in regard to clinical review, factor replacement prescriptions, etc. However, the Centre director had a maximum of a day and a half per week dedicated to the haemostasis and thrombosis service. In addition, he undertook a variety of other senior leadership and clinical roles within the team. His two consultant colleagues working in the service each had less than a day and a half a week for this service. For all of the consultants, this left no capacity for reviewing and managing the service, reviewing patient data and ensuring timely follow-up for all, or ensuring that documentation supporting the service was complete and updated as needed.

c. Physiotherapy: A named physiotherapist was in post, but within the allocated time was only able to undertake routine joint assessments. It was not clear what could be offered if any joint problems were identified at these assessments, and no comprehensive musculoskeletal risk assessments were seen. It appeared that joint problems sometimes reached clinically problematic levels before referrals to other services were made. The provision did not meet the UKHCDO standards of physiotherapy care.

d. Psychology: There was no psychologist working with either the paediatric or the adult team. A psychologist is expected to be part of the core team caring for these conditions. The team was therefore lacking the support and guidance that a psychologist can bring to the team's practice, and some patient and family needs were therefore not being met.

e. Social work: There was no named social worker available to support patients and families, and it was unclear whether the haemophilia team was able to access Trust-wide social care support easily. Other, already stretched, team members were helping families where they could; for example, both medical and nursing staff were taking time to help families navigate Personal Independence Payment (PIP) applications.

f. Data management: One member of the team was undertaking some data input work, but additional duties threatened the time she could spend on this. Even at current provision, it was not clear that all expected data submission was happening in a timely way or was complete. The Bristol CCC team registered and submitted data on the children with severe and moderate haemophilia, but not on the other children. The paediatric consultant lead was personally taking time to enter data onto his own local database.

Further Considerations

1. Patients who met the review team were not confident of the consistency of advice that they received from some teams outside the core team, especially out of hours. They felt that they were sometimes not listened to when trying to highlight to staff the importance of their bleeding disorder.
2. No formal clinical Multi-Disciplinary Team (MDT) was in place for patients with bleeding disorders, although informal communication between team members was frequent and effective. The fortnightly haemostasis laboratory meeting (attended by senior medical staff, nurse specialist, and biomedical scientists) could form the basis of such a meeting. Minuting this meeting would also be helpful in order that decisions could be included in the patient's clinical records, and for the benefit of team members who could not attend.
3. Some of the adult clinical guidelines were incomplete (see the compliances in Appendix 2), and some were not seen, including those on concentrate use and monitoring. A guideline for the care of patients requiring surgery was not seen. Where guidelines are not complete, or are not yet in place, it may be possible to share guidelines with the Bristol CCC.
4. The content of some of the clinical guidance was judged to be cautious. For example, the suggestion that patients with minor joint bleeds, or those who have had local anaesthetic dental procedures, should be admitted for overnight stay was not common practice elsewhere.
5. Patient information seen for adults did not cover the range of conditions, and some required updating. All patient information leaflets could be more widely displayed in the clinical areas and actively distributed to patients.
6. Copies of clinic and review letters were not always sent to patients. Reviewers heard that it was Trust policy not to copy all letters to patients. However, patients indicated that they would welcome more communication of this sort. Holding copy letters or another form of care plan is an expected standard, as a useful reference, knowing that patients may forget or mis-remember details of complex clinical conversations and decisions.
7. Reviewers learned that patients' medical records were in hard copy. An outline 'care plan' was included in them, behind the blue divider that started the haematology section of the records. However, it was apparent that other teams had not always seen or taken account of this; for example, the bleeding disorder diagnosis did not appear in

the problem lists in the letters from other specialists. The care plan, with its important disorder and treatment information, might be more prominent if filed within the front cover of the records.

8. The team learned that there was no 'alert' on the electronic patient system that was used when patients attended other hospital departments. It would be helpful if this could be established, for paediatric and adult patients, to ensure that all teams were immediately aware of their diagnosis, regardless of the reason they attended the hospital.

9. There was no system in place to ensure that potential or obligate carrier female relatives of patients were recalled for testing and counselling, before they reached reproductive age, although clinic conversations with familiar clinical staff usually led to this being discussed and offered.

10. The consultants with specialist expertise in haemostasis and thrombosis were thre e of 6.5 consultants in a 1:6 out of hours rota. When consultants with other sub-specialty interests were on call, they contacted one of the three for informal advice if there were particular clinical problems. It was considered that this cover would be more robust if formalised into a '2nd on call' rota between the three, especially as they were additionally providing cover for fourteen paediatricians operating the children's services out of hours cover, and only one of these paediatricians had bleeding disorders as a sub-specialty interest.

11. Some aspects of bookings for out-patient appointments were giving rise to problems. Patients reported that they often received their appointment letter for six monthly review only about two weeks before the appointment date, so that it could be difficult or inconvenient for them to attend. Also, where patients with bleeding disorders were booked into clinics other than the specific dedicated clinic sessions because, for example, there was a lack of capacity in those sessions, it was not possible to track this activity as part of the bleeding disorder service as it could not be distinguished from the other general patient throughput in other clinics.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Sarah Jones	Specialist Haemophilia Physiotherapist	Cardiff and Vale University Health Board
Lara Oyesiku	Haemophilia, Haemostasis and Thrombosis Network Clinical Manager	Hampshire Hospitals NHS Foundation Trust
Dr Rachel Rayment	Consultant Haematologist	Cardiff and Vale University Health Board
Paul Sartain	Patient Representative	

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

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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 also 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.

Service	Number of applicable QS	Number of QS met	% met
Comprehensive Care	37	21	57
Network	8	0	0
Commissioning	3	0	0
Total	48	21	44

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Haemophilia Centre

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)	N	Reviewers saw evidence of patient information leaflets. However, these did not cover all the requirements of this standard. Evidence was not available for (d), (e), or (h ii, iii, iv, v or vi).

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	However, not all the information seen was current, and information was not visible to patients in the clinic areas. Reviewers also heard from patients that they didn't feel that they were kept up to date by the team.

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.	N	Reviewers did not see evidence of a care plan that covered all aspects of this standard. Reviewers also heard from patients that they were not copied into clinical letters or outcomes of their reviews.
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.	N	See also HP-103. It was Trust policy not to copy clinical letters to patients.
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	See the Good Practice section of the main report.
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	N	Reviewers heard from patients and a carer that they did not feel that the wellbeing needs of patients' families and carers were discussed.
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 the Concerns section of the main report.

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 a template that would meet the requirements of this standard, but it was not populated with relevant staff details.
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	N	Complete statutory and mandatory training records were not made available for all members of the core team. In some cases, mandatory training was not up to date. **Trust response** – some were overdue due to lack of availability of courses.
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	N	See Concerns section of the main report.
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	However, reviewers heard from patients that their experience of the ED had not always been positive.

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	
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	N	The Trust did not have an electronic patient record system so could not meet the requirements of this standard
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	N	Reviewer did not see evidence of guidelines for all aspects of this standard.
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	N	Reviewers did not see evidence for inhibitor screening, immune tolerance therapy or dental care.
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	However, see HP-302 regarding the patient experience of the ED.

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	N	Reviewers did not see any evidence of a guideline relating to the care of patients requiring surgery.
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	
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	N	Reviewers heard that MDT meetings covering all the aspects of this standard were not taking place regularly.

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	Y	
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.	Y	
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	N	See Concerns section of main report (Staffing (f)).
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	N	Reviewers saw some evidence that audits, including on home delivery, patient satisfaction and concentrate use and waste, were in progress. However, the audits seen did not cover the requirements of this standard.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	N	Reviewers agreed with the Centre's self-assessment. There was very little research taking place, because of the capacity of the team.

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	See the Good Practice section of the main report.

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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	Reviewers did not see any evidence of network arrangements that met the requirements of this standard.
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	Reviewers did not see any evidence of network arrangements that met the requirements of this standard.
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.	N	Reviewers did not see any evidence of network arrangements that met the requirements of this standard.
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)	N	Reviewers did not see any evidence of network arrangements that met the requirements of this standard.
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	N	Reviewers did not see any evidence of network arrangements that met the requirements of this standard.
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 any evidence of network arrangements that met the requirements of this standard.
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 any evidence of network arrangements that met the requirements of this standard.

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	Reviewers did not see any evidence of network arrangements that met the requirements of this standard.

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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	N	Reviewers agreed with the Centre's self-assessment. There was a clinical paediatric network for children with severe bleeding disorders, but no adult network. There had been discussions regarding hub and spoke arrangements, but nothing had been agreed at the time of the review.
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 any evidence that these standards were regularly being reviewed by commissioners.
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 any evidence of regular review and learning meetings with providers and commissioners.

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