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

University Hospitals Bristol NHS Foundation Trust

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8831

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Introduction

This report presents the findings of the peer review of Services for People with Inherited and Acquired Haemophilia and other Bleeding Disorders at Bristol Haemophilia Comprehensive Care Centre (CCC) which took place on 21st March 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 Bristol NHS Foundation Trust
- NHS England and NHS Improvement 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 monitoring their implementation, liaising, as appropriate, with other commissioners.

Acknowledgements

We would like to thank the team at the Bristol Haemophilia Comprehensive Care 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 parents 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 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.wmqrs.nhs.uk

Bristol Haemophilia Comprehensive Care Centre

Bristol Haemophilia Centre was a combined adult and paediatric centre. There were dedicated adult and paediatric clinical staff who were appropriately trained. Administrative staff covered both services. The services were located in different hospitals within University Hospitals Bristol NHS Foundation Trust. All paediatric care was delivered in the Children's Hospital with age-appropriate facilities. Consultants from the adult services regularly attended paediatric haemostasis clinics to support transition to adult services and to provide continuity following pregnancy and the delivery of a child affected with a bleeding disorder where the diagnosis was expected. Both services were embedded within the wider haematology department, enabling the sharing of resources and, in some settings, of manpower. For example, in the Children's Hospital the haemophilia nurses also provided a benign haematology service including haemoglobinopathy.

Paediatric services covered the whole of the southwest, with twelve outreach clinics commissioned per year. A medical consultant, nurse and physiotherapist visited peripheral hospitals to provide haemophilia assessments in conjunction with local teams (both adult and paediatric haematology).

Whilst the Bristol Centre was the only Comprehensive Care Centre (CCC) in the southwest, the Centre did not feel that it was in a position to deliver a true clinical network, especially where adult services were concerned. They aimed to provide clinical support and advice to colleagues in Haemophilia Centres across the southwest and had been able to support the prescriptions of Emicizumab[1] for patients in Cornwall in a successful collaboration with the Haemophilia Centre team at Treliske Hospital.

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

Condition		No. patients	Severe	Moderate	Mild
Haemophilia A	Adults	148	47	10	91
	Children	75	34	5	36
Haemophilia B	Adults	26	6	2	18
	Children	18	5	4	8
von Willebrand	Adults	196	2	0	0
	Children	56	2	0	0
Other	Adults	181			
	Children	19			

Emergency Care

All patients registered with the Bristol Centre were issued with a haemorrhagic disorders card which gave contact details both in and out of hours. If Bristol was not the closest hospital, patients were advised to contact the Haemophilia Centre for advice.

When patients were admitted to University Hospitals Bristol, they had an alert on their electronic patient record that outlined their diagnosis and how to contact the relevant haematology team. All patients were set up on a clinical alert system that sent an email to Haemophilia Centre staff to highlight Emergency Department (ED) attendances, admissions, transfers and discharges.

[1] **Emicizumab** (trade name Hemlibra) is a humanized bispecific antibody for the treatment of haemophilia A. It functions in place of a natural blood-clotting factor that is missing in people with hemophilia A

As the adult and paediatric services were configured slightly differently, especially out of hours, there was guidance available for both services highlighting who to contact and where to access coagulation factors out of hours. Both the adult and the paediatric services had specialist out of hours cover for haemostasis and thrombosis, covered by consultants with expertise in these areas. The adult service had a haematology specialist registrar (SpR) on call 24/7 who had immediate access to the haemophilia consultant on call. The paediatric haematology / oncology SpR did not cover overnight but the general paediatric SpR would contact the on-call haematology consultant, where appropriate. If staff were not haemophilia trained, they would escalate to the on-call haemophilia consultant.

Out of hours, paediatric patients who needed clinical assessment were generally seen in the children's ED.

Adult patients were asked to contact the haematology patient emergency number and were triaged to be seen and assessed either in the Haemophilia Centre or in ED, depending on their presenting condition.

There was a programme of regular education for ED staff (particularly triage nurses), to ensure patients received appropriate treatment and referral.

Where patients attended hospitals outside University Hospitals Bristol, they were encouraged to show their haemorrhagic disorders card and contact the Haemophilia Centre.

Ward Care

Paediatric patients requiring admission were admitted to the relevant paediatric ward (haematology / oncology or adolescent ward). Where necessary, the haemophilia physiotherapist assessed and treated patients on the ward or in the physiotherapy gym.

Adult patients could be admitted to the speciality-specific ward, with the haemophilia team providing support and education regarding any clotting factor and appropriate investigations. Otherwise, there was a haematology ward located adjacent to the Haemophilia Centre. There was a programme of regular teaching for haematology ward and day unit staff.

Day Unit Care

Children were seen in oncology day beds in hours by the haemophilia team. On the rare occasions when there was no weekday haemophilia nurse cover (e.g. during periods of sickness or annual leave), day unit staff had appropriate training to manage these patients.

For adults, there was a dedicated haemophilia treatment room and access to chairs in the Haematology Day Unit. There were four haemophilia nurses, who cross-covered haemophilia, haemochromatosis, immune thrombocytopenia and Thrombotic Thrombocytopenic Purpura (TTP). The aim was to have a minimum of two nurses on duty each day, with staff covering from 7.30am some mornings and up to 9.00pm some evenings, depending on the rota. On the rare occasions when there was no weekday haemophilia nurse cover (e.g. during periods of sickness), the administrative team would ensure that non-urgent cases were cancelled, and the haematology day unit staff provided emergency cover.

Outpatient Care

For children, a dedicated haemostasis and thrombosis clinic run by clinicians and nurses with experience in managing patients with bleeding disorders, along with psychology support and physiotherapy assessment, was delivered in the paediatric haematology / oncology outpatient department.

For adults, clinics for severe patients were multidisciplinary, with a doctor, nurse and physiotherapist available. For milder disorders, the nurses ran ad hoc clinics either face to face or over the telephone every one to three

years, depending on the individual need and the severity of the bleeding disorder. Newly diagnosed or more complicated cases were assessed and seen by the clinicians in a separate outpatient clinic.

Community-based Care

Home and school visits were available for children when required. There were effective links with community nurses who could, for example, help to support families starting on prophylaxis who lived a long distance from the Centre.

Haemophilia nurses could provide home visits for adult patients, but these were becoming less commonly required by patients, as the younger adults were often in full-time employment. The nurses provided outreach visits to individuals who were unable to attend the Centre, such as those who had just undergone surgery or who were terminally ill. Nurses also attended the other hospitals in Bristol (especially Southmead Hospital) when patients were having surgery.

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Review Visit Findings

Achievements

Reviewers observed that this was a safe and very caring service. The multi-disciplinary team worked seamlessly across the paediatric and adult services in a co-operative, flexible and supportive way. The Centre was well led, in a non-hierarchical manner, with excellent team involvement and strong evidence of multi-disciplinary working. Psychology support to the team was limited, but the 0.2 Whole Time Equivalent psychologist supporting the paediatric service achieved a great deal, including undertaking some supervision, providing valuable support to families and on occasion also helping with patients using the adult service.

Patients and parents reported that the care they received when presenting to the Emergency Department (ED) was good, and they felt confident in the care that they would receive when they had to present acutely.

The paediatric network was well developed, with outreach clinics taking place twice a year at four linked sites. Although the adult network was not so well developed, linked hospital colleagues reported that they felt well supported, with easy access to clinical advice in and out of hours.

Patients and parents were appreciative of the Centre team, reporting that all of its members regularly went 'above and beyond' expected levels of care in their efforts to provide a good, patient-centred service.

Good Practice

1. Paediatric physiotherapy facilities were good. They were co-located with occupational therapy. The adult physiotherapy provision was also highly rated, with access to a hydrotherapy pool in which patients had developed a 'hydrotherapy club'. A rotating physiotherapist rota allowed for reliable cover at times when the dedicated haemophilia physiotherapist was not on site, and this also enabled a network of 'general physiotherapists' with a good understanding of haemophilia joint problems.
2. Inpatients between the ages of ten and eighteen years with a wide range of conditions, including inherited bleeding disorders, were managed on a shared inpatient adolescent ward, which was considered by reviewers to be an excellent model.
3. The Centre team were alerted by e-mail whenever an adult or child known to the service presented to ED or throughout University Hospitals Bristol.
4. A general hospital 'transition website' included a section for young people with haemophilia and von Willebrand's disease and covered a variety of topics including planning for travel. Team contact numbers were also available.
5. Transition practice was good. Adult haematology consultants worked in the paediatric clinic monthly, and paediatric nurse specialists attended with the young person at their first adult clinic appointment.
6. Some of the clinical guidelines were outstanding, in particular that for ED care; it was clear, colourful and systematic.
7. There was a good range of patient information, with links to sources of additional information.
8. Liaison with the laboratory team was good, with weekly meetings held between them and the clinical team at the Centre. Specialist laboratory staff also supported the biomedical scientists in the linked hospital laboratories.
9. A monthly evening clinic, held between 4pm and 7pm, allowed adult patients to attend without missing further education or work.
10. Young women with bleeding disorders were able to be seen in a paediatric gynaecology clinic.

11. Haemtrack[2] compliance rates were very high for patients registered at the Centre. Compliance at the time of the review visit was approximately 90%.

12. An alert system was in place with the South West Ambulance Service, so that staff were immediately aware of the patient's condition when a patient using the Exeter Centre required emergency care.

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

Concerns

1. **Staffing**

    a. There was no funded psychology provision for the adult service, and only a 0.2 wte psychologist working with the paediatric team. Reviewers noted that this was a significant gap, as psychologists form part of the expected core team for these services.

    b. There was insufficient administrative support for the paediatric team; specialist nurses themselves had to upload information recorded on hard copy at outreach clinics when they were back at the Bristol Centre.

    c. There was no social work support for the service(s). Patients noted that they needed help, for example in completing Personal Independence Payment applications. In addition, the team had recently lost a support worker who had provided an important point of contact for patients and families for non-clinical matters, and this loss was noted by the patients and parents who met the review team at the time of the visit.

2. **Network arrangements**

    Robust network arrangements for the care of adult patients across the southwest were not in place, and some patients had never been seen and assessed by the specialist team. Patients were offered appointments at the Comprehensive Care Centre by their local teams, but this could lead to some inequity of care as more mobile and more motivated patients could be seen, whereas those who might have more specialist needs may not be. The aim of the network should be that all patients – at least those with severe bleeding disorders – should be seen by specialist professionals on at least an annual basis.

3. **Fridges**

    Fridges containing supplies for both routine use and clinical trial purposes were unlocked in a room with a general staff 'swipe' access, so that any member of hospital staff could enter and access the supplies without restriction.[3]

[2] **Haemtrack** - Haemtrack is a secure recording system developed to connect patients and clinicians through the Haemtrack phone apps and website. Haemtrack enables patients to record all therapies as they occur and allows clinicians to see up-to-date therapy information to help monitor, optimise and improve patient care.

[3] The Centre confirmed that the fridge keys had been located soon after the review, and the fridge containing research products and the main factor fridge have now been locked. Importantly, whilst the room where the fridges is kept can be accessed by all staff who have access to the building, there is a log of those who have entered the room and so if there is a discrepancy in stock this could be investigated with relative ease.

Further Consideration

1. No guidelines were in place for the diagnosis and management of acquired haemophilia.
2. Guidelines for Immune Tolerance Therapy were unfinished, and the version seen at the time of the review therefore only covered initial management.
3. Diagnostic guidelines for Haemophilia A and B were good, but guidance for diagnosis of von Willebrand's disease and inherited platelet disorders were not seen.
4. Written competencies for adult patients who were self-administering factor concentrates at home were available but did not include reference to 'red flag' symptoms for which immediate professional assessment should be sought. This is especially relevant for patients with indwelling access devices.
5. Patients who had been treated for Hepatitis C were concerned about the lack of hepatology follow up. On discussion with the Centre team it was confirmed that those who had progressed to cirrhosis did have continued follow up. However, those who did not need ongoing hepatology input could be helpfully reassured on this point.
6. Some paediatric notes had been scanned into an electronic document system; however, this was no longer progressing as a new system was being planned. Those records which had been scanned were cumbersome and time-wasting for staff, as many historical records had been bundled together and scanned into a single file which could contain more than a hundred pages.
7. The range of laboratory tests available out of hours was limited to basic factor assays, and it was not possible to have inhibitor screens, factor Xlll assay, or platelet function testing at nights or weekends. The results of such tests can influence the immediate management of, for example, newly diagnosed patients and should be available in a Comprehensive Care Centre.
8. Parking on site was very limited and this presented substantial problems for patients, particularly those with mobility problems.
9. Some research studies were being run from the Centre, but adult and paediatric patients across the network were not always being offered entry into these.
10. There was no robust system in place for identifying and recalling all potential carrier females, usually expected at the age of 16. It was therefore possible for a carrier woman to become pregnant with an affected male baby without having been tested, so that appropriate care at delivery could not be planned.

Network

Although the paediatric network was well organised clinically, with outreach clinics at four linked hospitals, many other aspects of a managed network, as outlined in the Quality Standards, were not in place.

Additional support, resource and time will be required to develop the adult clinical networking arrangements and to allow a higher level of network functioning in other aspects, as outlined in the Quality Standards, including: education and training; audit; guideline sharing; review and learning; and research.

Commissioning

The Centre's self-assessment indicated that commissioners had agreed the configuration of the clinical network, including the relationships between the Comprehensive Care Centre and its linked centres, but the review team did not see evidence that specific commissioning arrangements, especially for the adult network, were in place.

It was acknowledged by the Centre team that network clinical quality review meetings and review and learning meetings attended by the commissioners were not taking place.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Stephen Classey	Clinical Specialist Physiotherapist Haemophilia	Guys and St Thomas' NHS Foundation Trust
Dr Nicola Curry	Consultant Haematologist	Oxford University Hospitals NHS Foundation Trust
Howard Doupe	Patient representative	
Lisa Gueran	Paediatric Physiotherapist	Oxford University Hospitals NHS Foundation Trust
Dr Kerry Ann Holder	Consultant Clinical Psychologist in Haemophilia and Child Health	Noah's Ark Children's Hospital for Wales
Helen Hupston	Clinical Nurse Specialist	University Hospitals Birmingham, NHS Foundation Trust
Dr Kate Khair	Clinical Academic	Centre for Outcomes Research and Experience in Children's Health Illness and Disability (ORCHID). Great Ormond Street Hospital for Children NHS Foundation Trust
Dr Fernando Pinto	Paediatric Haematology Consultant	Royal Hospital for Children, NHS Greater Glasgow and Clyde

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

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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 varied 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

	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	31	84%
Network	8	0	0%
Commissioning	3	0	0%
Total	48	31	65%

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Haemophilia Comprehensive Care Centres and Haemophilia 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	Reviewers saw a wide range of materials available for patients, carers and their families.

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	Reviewers could not see anything documented for patients in relation travel advice. However, the Centre confirmed that information was given to patients to take on holiday to allow them to carry their factor, and the Centre would always advise them where the local haemophilia centre was; in addition, the Haemtrack app identifies the nearest Haemophilia Centre to a patient's location. Patients were also directed to the Haemophilia Society for additional information.

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	Evidence was seen for the Bristol Centre but not for the network.

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	Reviewers particularly liked the adult physiotherapy facilities and the adolescent ward.
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	Reviewers felt that the transition website was particularly good. Some transition information is patient specific and is therefore provided specifically during the meetings with consultants.
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 agreed with the Centre's self-assessment.
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 Centre's self-assessment. In addition, reviewers noted that there was no psychology input for adult services and no social worker input (which patients and carers felt would be helpful). See also the Further Consideration section of the main report regarding the loss of the family support worker and lack of administrative support for the network.

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.	Y	
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	Whilst reviewers saw that there were robust arrangements in place in relation to liaison between the Comprehensive Care Centre and the other centres in the network, and were impressed that there were weekly meetings with the laboratory, reviewers were concerned that, although it was a Comprehensive Care Centre, the laboratory did not offer all factor assays, inhibitor screening, or platelet function tests seven days a week.
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 the main report in relation to accessibility to research fridge.
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	N	Reviewers did not see any evidence for c-f and noted that the procedure for identifying and then following up potential carrier women at age 16 needed to be more robust.

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	Reviewers felt that the detail for c, Immune Tolerance Therapy, were under review and needed completing.
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	See Good Practice section of the main report.

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	
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	Reviewers did not see a written guideline for school visits.
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	Reviewers noted that these meetings were well documented.

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	See also HP-202: there was no provision for social work or psychology input into MDT meetings or clinics.
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	Although there was regular contact with other services, the requirement of this Quality Standard is for annual meetings, which were not taking place.
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	N	Reviewers agreed with the Centre's self-assessment.
HP-706	**Research** The service should actively participate in research relating to the care of patients with bleeding disorders.	Y	See Further Consideration section of the main report regarding the potential of inviting patients from other hospitals in the network.

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	

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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 agreed with the Centre's self-assessment.
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 agreed with the Centre's self-assessment.
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 agreed with the Centre's self-assessment.
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 agreed with the Centre's self-assessment.
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 agreed with the Centre's self-assessment.
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.	N	Reviewers agreed with the Centre's self-assessment.

Ref	Standard	Met?	Comments
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 agreed with the Centre's self-assessment.
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 agreed with the Centre's self-assessment.

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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 did not see any evidence at the time of the visit that this was in place for adult or paediatric patients.
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 agreed with the Centre's self-assessment.
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 agreed with the Centre's self-assessment.

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